

**PSYCHOGENIC NON-EPILEPTIC SEIZURES:  
A SELF-DIRECTED LEARNING MODULE FOR NURSES**

by © Daniel Robinson A Practicum Report submitted  
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## Abstract

**Background:** Psychogenic non-epileptic seizures (PNES) are the result of underlying psychopathology and ineffective coping responses. People with PNES represent a significant proportion of admissions to diagnostic epilepsy units. Nurses who are new or inexperienced working in epilepsy units are unaware of the presence of patients who have PNES and as result, are unprepared to provide individualized nursing care to this patient group. **Purpose:** The purpose of this practicum was to develop a self-directed PNES learning module for nurses to augment the current nurse orientation education with an aim of developing PNES knowledge and sensitivity in nurses before they are assigned their first patient. **Methods:** Three methodologies were used and completed in this practicum which included an environmental scan, a review of the literature and consultations with key stakeholders. **Results:** The self-directed PNES learning module was composed of three units which included explanations of key terms essential to nursing care and engagement of the patient who has PNES. Themes of advocacy and compassion are central to the body of work. **Conclusion:** The goal of the practicum was achieved in its delivery of a resource which provides a means to resolve the learning needs of novice or inexperienced nurses transferring into diagnostic epilepsy units. The practicum has produced a tangible means to improve the nursing care provided to patients who have PNES by developing competency and sensitivity in nurses tasked with providing individualized care to these patients.

*Keywords:* Psychogenic non-epileptic seizures, PNES, self-directed learning module, epilepsy nurses, education

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## **Introduction**

Psychogenic non-epileptic seizures (PNES) are caused by underlying psychopathology which is expressed as a predisposed individual attempts to cope with stress via flawed internal processes. PNES is a common condition for some individuals in a diagnostic epilepsy unit with 20-40% of all referrals to the unit receiving a diagnosis of PNES (Martin et al., 2003; Asadi-Pooya, & Sperling, 2015). Adapting this estimate to the local context, a discharge diagnosis of PNES will have been provided to about 144 of the 359 patients admitted the diagnostic epilepsy unit at London Health Sciences Centre (LHSC), London, Ontario (London Health Sciences Centre, 2016). Given the established presence of non-epileptic patients in epilepsy units, it is imperative that the nursing care provided to all patients is holistic in nature and tailored to the needs of the individual. Hence, an epilepsy-centric model to patient care can leave important precipitants unaddressed and may also adversely affect the functioning of the individual.

This practicum project has its roots in an anecdotal observation which I made during my orientation to the Epilepsy Program at LHSC as the new coordinator of the unit and clinical team. An early and key learning from my observing clinical practice was that patients with PNES appeared to be underserved by diagnostic epilepsy units. Further to this end, it was suspected that nurses who were inexperienced working in diagnostic unit practice settings or those who are naïve to the needs to a patient with PNES could act as a barrier to treatment and recovery in these same patients. A cursory inquiry into the experience of people with PNES revealed healthcare for this population is often

uncoordinated resulting in a pervasive gap in healthcare. Additionally, this early inquiry also exposed a paucity in the literature surrounding effective nursing in-patient care models for PNES. This knowledge prompted the identification of a need for the development of a self-directed learning module for nurses focusing on PNES as a goal for the practicum project.

The epilepsy monitoring units are the hospital-based inpatient programs to which patients are admitted may receive a diagnosis of PNES if their seizures are determined to be non-epileptic; it is imperative that these units are ready to provide health resources. Also, the availability of these resources has the potential of influencing long term outcomes for these individuals/families. Epilepsy diagnostic units must offer patients with PNES more than a diagnosis. Patients who are determined to have seizures which are non-epileptic in origin require resources and support to positively manage their health condition if deleterious outcomes associated with the PNES are to be mitigated or avoided for them.

An orientation inclusive of PNES education to nurses who are transitioning into the diagnostic epilepsy unit will assist in preparing nurses to develop and initiate care plans which meet the needs of the individual/family. This self-directed learning module for nurses aims to positively influence outcomes for the PNES population by creating the conditions for nurses to collaborate with patients in their recovery or healthcare journey. Nurses must possess the knowledge to appreciate the experience of people with PNES and appreciate their obligation to provide needs-based care to patients with this diagnosis.



A self-directed learning module for nurses when embedded into the orientation of nurses to the diagnostic epilepsy unit will prepare nurses to work with the patients who have PNES and require informed nursing care.

### **Background**

The setting for the practicum project was the diagnostic epilepsy unit known as the Epilepsy Monitoring Unit (EMU) which is embedded as part of the Clinical Neurosciences Program at LHSC. The EMU provides diagnostic and surgical inpatient care to individuals with possible or confirmed epilepsy. In cases of diagnosis, electrodes are attached to patients and concurrently monitored by video camera to capture both brain activity and the physical expression of seizure events for review. LHSC is a clinical teaching hospital in London, Ontario caring for the medically complex and critically ill patients in region. This ten-bed unit is the largest in Canada and has a robust multidisciplinary healthcare team that will admit about 360 patients from around the world annually. The unit is staffed by four nursing teams composed of a Registered Nurse (RN) and a Registered Practical Nurse (RPN) each. Vacation relief and sick coverage is provided by casual or off-service in-patient nurses, as well as the nursing reserve float team which can present variation and limitations in the PNES experience and nursing knowledge related to PNES.

### **Goal and Objectives**

The goal which underpinned the practicum project had been to increase PNES knowledge amongst nurses orienting to the diagnostic epilepsy unit. The orientation of novice or

inexperienced nurses working in a diagnostic epilepsy unit advocates for a unit culture which has an appreciation of what a diagnosis of PNES can mean to a patient/family. An orientation of nurses to the diagnostic epilepsy unit which is inclusive of PNES education will facilitate the consistent delivery of evidence-informed nursing care which is consistently provided to patients with PNES.

The practicum objectives which were addressed during the practicum were:

1. To uncover themes and interests central to PNES by completing an extensive review of the literature surrounding PNES as a population health.
2. To determine the standard PNES-specific training epilepsy unit nurses receive in preparation to work with patients who have PNES by completing an environmental scan of national and international epilepsy programs.
3. To inform content for module inclusion by consulting experts and the multidisciplinary epilepsy team
4. To develop a self-directed PNES educational module for nurses to be part of comprehensive approach to orientation to the diagnostic epilepsy unit and nurse education.
5. To produce a final practicum report which is demonstrative of advanced nursing practice with the PNES education resource being representative of competency in each domain.

Advanced nursing competencies are imbedded into the objectives for this practicum and are aligned using an integrated and holistic approach to a health education intervention. An appropriate depth, breadth and range of theory, research, nursing knowledge and clinical experience form the core of advanced nursing practice (Canadian Nurses Association, 2008). Built upon this core are the clinical, research, leadership and consultation which are the four competencies of advanced nursing practice. The objectives are demonstrative advanced nursing competencies and engage team members in resolving population health and patient care issues at individual, organizational and healthcare-systems level. All competencies have been supported by scholarly inquiry and an evidenced informed approach.

### **Methods**

A total of four methodologies were selected to achieve the practicum project objectives. These methods included the following: (1) a review of the literature, (2) consultations with experts and the multidisciplinary team (3) conducting an environmental scan and (4) the development of the self-directed learning module for nurses on PNES. These are summarized in the following report. Approval from the Health Research Ethics Authority was not required for this project; the completed screening tool can be found in Appendix B.

### **Summary of Integrated Literature Review**

An extensive literature review was conducted. Scholarly articles for the literature review was obtained from searching CINAHL, PubMed and MEDLINE databases and included

results from the Cochrane Library. No results were found for publications related to PNES educational modules for nurses working in diagnostic epilepsy units. Search keywords included ‘PNES’, ‘seizure’, ‘non-epileptic’, ‘nursing education’, ‘epilepsy e-learning’. The search was limited to English language publications and search parameters were expanded to include publications from 2005 to present due to a lack of viable results. Emergent themes from the integrative literature review were: (1) life experiences of people living with PNES, (2) coping strategies typified by people with PNES and (3) the importance of healthcare providers in relation to PNES care provision. The complete integrated literature review will be found in Appendix A.

### **Theme One: Life Experience of People Living with PNES**

Living with PNES means living with stress, risk, angst and vulnerability. PNES are life altering paroxysmal events which have wide sweeping implications for people who experience or live with the symptoms. PNES stems from factors associated with an individual’s biology or psychology as opposed to being the result of excessive and unrequited neuronal activity. This also serves as the basis for contrast between PNES and epilepsy (Pillai, Haut, & Masur, 2015). PNES is understood to be the result of ineffective coping in response to stressors (Rawat, Dhinman, Sinha, Sagar, & Thippeswamy, 2015). Stressors, in isolation or in combination, which populate the individual’s environment, psychology, biology or psychosocial domains may precipitate seizure activity in those with a predisposition for responding to stress by seizing (Turner et al., 2011; Kanner et

al., 2013; Kaplan et al., 2013; Elliot & Charyton, 2014; Gubbi et al., 2015; Pillai, Haut, & Masur, 2015). Physical and sexual trauma is very common amongst people with PNES which may also have a compounding relationship with impaired emotional processing and the characteristic ineffective or maladaptive coping (Kaplan et al., 2013; Say, Tasdemir, Akbas, Yüce, & Karabekiroglu, 2014; Barzegaran, Carmeli, Rossetti, Frackowiak, & Knyazeva, 2015; Wichaidit, Ostergaard, & Rask, 2015). Psychiatric illness and psychological deficits are very much associated with PNES and will also emerge longitudinally as additional stressors which may promote seizure activity in those with the predisposition (Patidar et al., 2013; Duncan et al., 2014; Say, Tasdemir et al.; Beghi et al., 2015; Pillai, Haut, & Masur, 2015; Rawat, Dhinman, Sinha, Sagar, & Thippeswamy, 2015).

People seeking help with PNES experience challenges accessing specialized care (Pretorius & Sparrow, 2015). PNES are frequently diagnosed as intractable epilepsy and as a result, patients presenting with non-epileptic seizures may be prescribed antiepileptic medications which can be harmful and may result in further healthcare utilization (O'Sullivan, Redwood, Hunt, McMahon, & O'Sullivan, 2013; Duncan et al., 2014; Santos, Benute, Santiago, Marchiori, & Lucia, 2014). When access to specialized care is made available or otherwise achieved, interventions have demonstrated to improve severity and frequency of seizures, and decreased healthcare utilization. Self-reported measures related to quality of life, however, do not improve despite reduced seizure activity (Mayor et al., 2012). Impaired social functioning secondary to psychological distress has been associated with increased interpersonal conflict which has a relationship

with anxiety, depression and decreased quality of life in people with PNES (Myers, Lancman, Laban-Grant, Matzner & Lancman, 2012; Hendrickson, Popescu, Dixit, Ghering, & Bagic, 2012; Say, Tasdemir, Akbas, Yüce, & Karabekiroglu, 2014).

Psychological distress may act as a precipitant of or emerge in response to both predictable and capricious elements associated with PNES. These intrinsic PNES elements can develop and potentiate a negative feedback loop which further exacerbates a hard-hitting individual context.

### **Theme Two: Coping Strategies of People with PNES**

Coping with PNES and the constellation of associated difficulties can be understood to be an individual's attempt to manage the circumstances which emerge from the interaction of these variables. For people with PNES, attempts to cope often involve the use of defense mechanisms which tend to be ineffective and deleterious in relation to global functioning (Beghi et al., 2015). Coping strategies are typified by avoidance, suppression and impoverished emotional experiences (Novakova, Howlett, Baker, & Reuber, 2015). Emotion-driven behaviours and avoidance are characteristic strategies typically employed by people with PNES to cope (Acton & Tatum, 2013; Meyers, Fleming, Lancman, Perrine, & Lancman, 2013). Coping with PNES can elicit additional challenges. For example, if the individual selects an inappropriate strategy, this response can inflame circumstances significantly and possibly present new stressors for the individual to negotiate with a coping response.

People with PNES attempt to cope with their seizures by presenting to healthcare providers to help obtain a healthcare response. Presenting to healthcare as a means to cope can provide access to care, medication and monies which can be advantageous as it relates to global health for those who have PNES (Duncan et al., 2014; Novakova, Howlett, Baker, & Reuber, 2015). Seeking help from healthcare providers may not always be beneficial for people with PNES and in many cases can prolong the ruinous conditions which often surround untreated PNES (Pretorius & Sparrow, 2015).

Individuals who have been placed on an incorrect treatment path by way of an incorrect medical diagnosis are likely to be exposed to antiepileptic medications which can be very harmful pharmacological agents (Kanner et al., 2012; Santos et al., 2014; Duncan et al., 2014). People who experience PNES appear to be ‘hardwired’ for an ineffective coping response which connects the internal to the external, cognition to emotion whilst producing context for the associated psychological distress in which the coping response is expressed as seizure activity (van der Kruijs et al., 2012; Meyers, Lancman, Laban-Grant, Matzner & Lancman, 2012; Meyers, Fleming, Lancman, Perrine, & Lancman, 2013; Elliot & Charyton, 2014; Novakova et al.). The confluence of circumstance as it relates to a person with PNES is of primary importance to healthcare providers seeking to engage a patient, understand their presentation and in deed, help the person to cope with life.

### **Theme Three: The Role of Healthcare Providers**

Healthcare providers (HCPs) are positioned along the healthcare continuum to assist individuals and families to restore health and balance in healthcare situations. HCPs can also guide and direct patients through their healthcare journey whilst possessing tremendous influence over the direction and trajectory of specific and future healthcare encounters. These healthcare encounters can be advantageous for the patient or they can be detrimental. Emergent from the literature is a triad of themes relating to the role of HCPs: 1) Access to care 2) Barriers to care and 3) The approach of the healthcare team. Truly, it is the outcomes of a person with PNES who has presented for health care which can be influenced depending on the how and by whom health care is delivered to them. Persons with PNES visit to healthcare institutions, programs and professionals for support, information and therapeutics (Santos et al., 2014; Duncan et al., 2015; Gubbi et al., 2015; Pretorius & Sparrow, 2015). When HCPs provide access to appropriate specialized care for PNES, outcomes are very favourable in relation to baseline seizure occurrence and healthcare utilization (Mayor et al., 2012; Martlew, Pulman and Marson, 2014; Santos et al., 2014). Also, in situations where healthcare for the individual is managed correctly, PNES can resolve and patients can remain seizure-free following individualized intervention (Mayor et al., 2012; Patidar et al., 2013; Rawat, Dhinman, Sinha, Sagar, & Thippeswamy, 2015).

The emergency rooms of hospitals have the potential to be transformative milieus when people with PNES present seeking collaboration with HCPs. When emergency department health care teams refer to specialized diagnostic units or tertiary care programs, the seizures of people with PNES are more likely to be correctly identified as



PNES, which reduces exposures to antiepileptic agents and promotes an improved individual and caregiver experience with non-epileptic seizure expression (O'Sullivan, Redwood, Hunt, McMahon, & O'Sullivan, 2013; Karakis et al., 2014; Duncan et al., 2015). Once the diagnosis of PNES is made, access to specialized care for those who engage in treatment has demonstrated to promote very favourable outcomes in relation to emotional and somatic well-being, quality of interpersonal relationships, healthcare utilization and seizure frequency (Kanner et al., 2012; Mayor et al., 2012; Myers, Lancman, Laban-Grant, Matzner, & Lancman, 2012; Duncan et al., 2014; Santos, Benute, Santiago, Marchiori & Lucia, 2014).

Perhaps the greatest barrier to people seeking healthcare for PNES are HCPs. Conceivably more damaging than inexperience, the negative attitudes and stigma in relation to PNES which lives within healthcare teams and amongst providers (Pretorius & Sparrow, 2015). Negative attribution to PNES, such as 'fake', attention seeking or the seizures being under volitional control, is very common amongst nurses which may influence interpersonal nursing dynamics and quality of nursing care (Sahaya, Dholakia, Lardizabal, & Sahota, 2012). While instrumental to formal interventions for PNES, healthcare providers can also be a barrier to care, treatment and resolution. Beyond this, naive or inexperienced healthcare providers may in fact, prolong time to diagnosis, control access to specialized diagnostic and medical care for people with PNES while exposing individuals to detrimental pharmacological agents.

### **Nursing and Knowledge Acquisition**

As was discovered in the search for PNES education material for nurses, no literature was found for studies which focused specifically on how to teach nurses working in diagnostic epilepsy units about PNES. The search did return results which have been organized into three central themes: (1) Impact of e-learning on nurses, (2). PNES training and (3) epilepsy-based e-learning for nurses. These three themes will be discussed as major headings and will inform the examination of PNES and how nursing education can support practice improvement and PNES population literacy in nurses.

### **Impact of e-Learning on Nurses**

The Canadian Nurses Association declares it is only through education that nurses can meet the demands of contemporary healthcare practice environments (Canadian Nurses Association, 2016). Technology enabled delivery of education, or e-learning, has become a common mode of instruction in the education of nurses and nursing students. Nursing has endorsed the utilization of e-learning as a flexible and convenient means to educate nurses and nursing students in the provision of both basic and post-basic education (Button, Harrington & Belan, 2014; Lahti, Hatonen, & Valimaki, 2014; Liu, Chu & Chen, 2014; Liu, Rong, & Liu; 2014). E-learning has been demonstrated to be an effective method to improving knowledge and skill enhancement in nurses (Bloomfield, While, & Roberts, 2008; Du et al., 2013; Petty, 2013; McCutcheon, Lohan, Traynor, & Martin, 2015).

### **Psychogenic Non-Epileptic Seizure Education**

Preparing nurses to engage people who experience PNES requires the provision of education surrounding the health condition and the experience of people who live with or in proximity to the seizures. Education specific to PNES is central to assisting nurses to effectively respond the unique needs and coping styles of people presenting with PNES to (or have already been) engaged in the healthcare system (Sahaya, Dhloakia, Lardizabal, & Sahota, 2012; Yates, 2014). When nurses in epilepsy monitoring units are exposed to education relating to non-epileptic seizure identification, translation to practice takes place. It is also through education that nurse practice enhancements are sustained into follow-up and future nursing situations (Isler et al., 2008; Lochareernkul, Suwaroporn, Krongthong, Limarun, & Arnamwong, 2010; Stecker & Stecker, 2012). There is promise that these results can be translated into PNES education.

### **Theoretical Framework**

The current review of PNES literature is augmented by a complementary review of literature which comments on the tenants of adult learning, characteristics of adult learners and conditions which promote learning in nurses. This section will discuss Knowles (1984) Theory of Adult Learners, Kolb (1974) Theory of Experiential Learning theory of experimental learning and learning style inventory is related to the Benner's (1984) description of the progression from novice to expert.

#### **Knowles' Theory of Adult Learner**

In contrast with classical pedagogy, andragogy is a learner as opposed to a teacher-centered conceptualization of how and why adult learners learn which also has

implications for how adult learners can be motivated to receive instruction. Andragogy is characterized by an emphasis on the teacher facilitating the acquisition of knowledge in the adult learner by using an approach which draws upon the learner's prior knowledge to challenge ideas or problems or to integrate new concepts into one's schema (Knowles, 1977; Yates, 2014). A forerunner in the development of Adult Learning Theory was the work of Malcom Knowles who introduced six core principles to organize the assumptions surrounding the instruction of adult learners (Norrie & Dalby, 2007; Clapper, 2010).

### **Kolb's Experiential Learning Theory and Learning Style Inventory.**

Complementing the work of Knowles, Kolb's abstractions of adult learning also acknowledges experience as a resource for learning and participation the means to learning. The experience of learning has a crucial influence on the learning process for adult learners. In his theory of experiential learning, Kolb presented a cyclical construct of adult learning which consists of four distinct stages each underscoring the "essentiality of practical experience to the learner's knowledge development" (Cooley & De Gagnon, 2016, p. 97). When Kolb's stages of learning are paired with an appreciation of learning style, learning can be tailored and made accessible to people with a particular predisposition to acquiring knowledge, as well as influencing motivation to continue learning. In relation to learning module design, it will be important to consider the potential for all learning styles to be present in the membership of the unit's nursing staff.

### **Benner's Description of Clinical Competence: Novice to Expert**

Benner (1982) described a series of stations which nurses pass through as they acquire knowledge and gain experience moving through five levels of nursing proficiency marking the transition from novice to expert. The description provided by Benner in relation to the progression of a nurse from novice to expert is representative of a fluid gating framework which permits advancement as mastery of nursing practice develops. The acquisition of nursing education and skills to be integrated or honed by nursing practice serves as the means by which nurses advance from novice to expert. A criticism of the novice to expert description put forward by Benner is that nursing practice can be learned; it cannot be taught to the individual. This suggests that advancing beyond novice requires predominantly the accumulation of formative experience via nursing practice (Gardiner, 2012).

### **Summary of Consultations**

The participants for the consultations were considered carefully. It was acknowledged early on that the groups of nurses working in the diagnostic epilepsy unit are a principal source of information. The experience of nurses not only working with patients who have PNES but also their experience working with novice and inexperienced nurses with PNES would be of considerable value. The consultations served to both confirm the need for a learning module and its content. The intention for the nursing consultations was to capture all of the epilepsy unit's primary nursing staff and it was truly fortunate that opportunity presented itself to consult two casual nursing staff members. Of incredible relevance to the current practicum project was the opportunity to consult a nurse who had

just joined the team from another hospital service prior to her first exposure in the unit. In total, 10 nursing consultations were completed with an additional consultation completed with a burgeoning epilepsy nurse. The consultations completed with the nursing staff were comprised of meetings with nurses who possessed varied levels of nursing experience and exposure to nursing activities in a diagnostic unit.

The selection of experts for consultation was informed via PNES- associated environmental scan. The environmental scan served to recognize and suggest individuals who could inform the project from a perspective different than nursing promoting a diverse, robust and holistic approach to learning module creation. Participants sought for consultation included professionals within the Epilepsy Program itself, local community organizations, as well as individuals from national and international diagnostic epilepsy units. The professions identified for consultation included membership from diverse disciplines such as physician neurologists, social work, neurodiagnostic administration, community education specialist, psychology and from a nurse practitioner. In total, six of eight consultations with identified experts were able to be completed. Unfortunately, two of the experts could not be reached for consultation due to relocation and a retirement.

The themes which emerged from this process were used to identify content and structure a self-directed nursing PNES learning module. Interestingly the emergent from the data collection mirror in some ways, the themes present in the critical review of PNES literature.

A theme which was recognized by all groups consulted was the need for an accessible overview of PNES. This information is regarded as being paramount to a nurse being able to effectively support the individual with PNES and to both understand the development of non-epileptic events but also to anticipate the needs of an individual with this condition. It was suggested by several respondents that an overview which included the origin of PNES, semiology and how diagnosis is made as well as delivered would be specifically assistive to preparing nurses to work with this inpatient population.

The role of the healthcare provider (HCP) was also a central theme. It was identified that HCPs can act as a barrier and a facilitator of healthcare. When the role of a professional is poorly understood by others on the healthcare team or the patient, the healthcare system can work against individuals with PNES. Role-related knowledge deficits have been suggested to impose barriers upon patients with PNES by limiting access to service or delaying time to recovery. The role of the nurse was considered to be significant by those consulted. Importance was not only placed on the role of the nurse in relation to being omnipresent in the unit to help the individual cope during a non-epileptic event. It was also noted that if a nurse is unprepared, the nursing actions which compose the care for the individual are likely to be misguided and in some cases, harmful or damaging to the individual. A reassuring subtheme of the role of experience as it relates to developing nursing competency in relation to assessment and management of PNES. By supporting individuals with PNES with a sensitive evidence-informed to nursing care, nursing aptitude will improve with exposure to individuals who have PNES and experience in the diagnostic unit.

A theme which was identified through analysis was the patient's life experience inside and outside of the diagnostic epilepsy unit. This theme encompasses experiences that people with PNES being stigmatized or marginalized by individuals and systems but also comments on the individual's to health care and as a recipient of health care as a life experience. The consultations provided insight into a number of key issues relating directly relating to or surrounding the creation of a self-directed PNES learning module for nurses.

The expert consultations wholly established the need for improved nursing care delivered to patients with PNES in diagnostic epilepsy units. It was also confirmed that this end could be attained through targeted education of nurses working with this patient population. expert and nursing consultations were particularly informative in relation to the reflections related to being new and the anticipation of what newly hired nurses who are new to the diagnostic unit are likely encounter in practice and therefore need to be prepared for. The nursing consultations revealed the nursing staff to be a remarkable source of experiential learning for new nurses but noteworthy is that not all nurses regarded themselves as possessing adequate knowledge relating to PNES to teach other/new nurses. The consultation with the new nurse confirmed that new nurses are very much unaware of the presence patients with PNES in the unit and as a result, are understandably underprepared to work with patients with PNES. Nearly all nursing respondents acknowledged that the Epilepsy Program could be doing more for patients with PNES while they remain patients of the diagnostic unit.



## **Environmental Scan**

The local, national and international environmental scans confirmed that formal hospital-based PNES programs, practiced healthcare providers and PNES-specific community support for people with PNES is fractured at best and non-existent in many cases.

Considerable variation was observed in relation to the degree to which diagnostic epilepsy programs outwardly acknowledged the presence of patients with PNES in their epilepsy units and only one service offered treatment to this population. The environmental scan also exposed professional, geographical and organizational inadequacies which act as barriers to recovery for people who have this diagnosis.

## **Development of the Learning Module**

The self-directed learning module was a focus of the second practicum term and has consolidated the foundational work completed in the earlier term. The self-directed PNES learning module for nurses was developed as an amalgam of key insights, observations, themes and commentaries on lived experience originating from the foundational environmental scan, literature search and consultations. These core elements were used in synergy to develop the content for the learning module and the layout of the work. Three units were designed to be connected yet conveying information which was distinct in its objective. Stepwise progression strategy was used to develop and build upon important elements or themes related to PNES nursing education. The learning module is written for application to both RNs and RPNs with consideration for the disparity in academic preparation and heterogeneity of nursing experience or exposure to PNES. The self-

directed learning module for nurses has been created to adapt well to the local context and delivers an informed approach to educating nurses about PNES from exploration of the literature, scanning the environment and consulting experts.

The initial unit of the module is an overview of PNES which is reflective of an expressed need from the consultations and was alluded to by the literature. The overview is formative in its introduction of how an individual with PNES would come to be admitted to an epilepsy unit. The overview is also very overt in its legitimizing of PNES as medical condition which requires individualized nursing care. Building upon the overview of PNES, the second unit of the module proceeds describe of the roles of diagnostic unit healthcare providers and their contribution to patient care. Describing the roles of healthcare providers emerged from consultation as a deficit for nurses who are inexperienced working in epilepsy units and patients with PNES. The second unit was designed to introduce novice or inexperienced nurses to the roles of the healthcare providers working on the multidisciplinary team. The relationship between each healthcare provider and the patient who has PNES is explored and connected to nursing assessment and care planning. This module in particular helps to establish the interconnectedness of the multidisciplinary team and cements the importance of nursing PNES-related proficiency from the point of view of the patient and the membership of the team alike. The final unit is an elaboration on the life experience of someone with PNES. Consultation with a newly orienting nurse to the unit confirmed that nurses coming to the unit are naïve to the individual who has PNES. Furthermore, the factors which influence their lives or act as barriers to access, healthcare and the objectives of PNES treatment,

recovery and self-actualization were novel fundamentals as well. The first two units conclude with an opportunity to test comprehension. Testing the comprehension of the learner also acts to afford gated progression through the module ensuring concepts are understood before the learner moves on. In the final unit, a case scenario and questions to promote operationalization prior module content are presented to the learner to stimulate reflection and ensure the implications PNES has for some patients are considered.

The design of the self-directed learning module and the details or features used to engage the learner is also very much considerate of the intended audience and the local context. Each learning module unit also contains appendices which augment unit material by providing further elaboration and additional learning of key concepts or guidelines. The use of graphics/illustrated representations and the use of text styles had been considered carefully in relation to the intended audience and purposefully communicate subtle messages to the learner. The use of the stethoscope graphic has been used to distinguish PNES as a legitimate medical condition by introduced to the module early and carried throughout the first unit. The colour purple is associated with epilepsy awareness and purple text was selected to help PNES integrate into established epilepsy unit culture. Important information is made to stand out from the unit by separating out these details and was paired with a 'key' graphic to capture the attention of the nurse learner. Comprehension and application of knowledge was also considered in the development of the self-directed module. Throughout the module, advocacy and the promotion of a stigma-free healthcare environment are major influences. The power of stigma in relation to PNES and the impact the condition has on a person's social functioning, interactions

with healthcare professionals, access to service and recovery are profound. The information presented in the self-directed learning module has been designed with the needs of the nursing audience in mind. The module will have its ultimate application in the orientation of RNs and RPNs with varied degrees of experience, education and exposure to PNES related nursing situations. Educating nurses about the needs of patients with PNES at orientation will prepare nurses to purposefully engage patient using an evidence informed approach to nursing care planning and delivery.

### **Advanced Nursing Practice Competencies**

Advanced nursing practice (ANP) is a standard of excellence which can be evidenced by the integration and application of nursing theory, nursing knowledge, nursing experience and nursing research into nursing interactions. The Canadian Nurses Association describe competency in *Advanced nursing practice: A National Framework* (2008) and organized ANP into four categories: Clinical Competency, Research Competency, Leadership Competency and the Consultation and Collaboration Competency. The national framework explains advanced nursing practice is incredibly sophisticated. Progression through the practicum has been demonstrative of ANP and all four competencies can be evidenced in the output of the practicum experience.

### **The Clinical Competency**

Comprehensive and holistic care can be considered a hallmark of the sound clinical nursing care. The clinical competency is demonstrated through the integration the dynamic and complex factors influencing the patient who has PNES but also those which

influence nursing care to this same patient. Clinical competency is evidenced by the identification of an underserved patient population in the diagnostic epilepsy unit. The clinical assessment skills which I had developed as a practicing mental health nurse are entrenched in the topic of the current practicum as well the attitude of the module and its content. An appreciation of the needs of a patient with PNES and that normative nursing care provided to these patients was as inadequate as it was indifferent. Developing clinical competency in other nurses, particularly those who are transferring into a role with the diagnostic epilepsy unit is a principle aim of the current learning module. The clinical competency in the engagement of the multidisciplinary team, as well as other members on the care continuum to partner in the pursuit of comprehensive nursing care provision to patients with PNES in diagnostic units.

### **The Research Competency**

The research competency has been demonstrated in the synthesis and operationalization of research evidence to inform the consultations and the self-directed learning module as an end product. In the current project, the use of research driven innovation is intended to improve the care of the patient with PNES in a system where this patient currently has historically been underserved. Moreover, the research competency was evidenced by the critical appraisal of scholarly literature of which the integration of the literature review and the environmental scan were demonstrative. Future iterations of the self-directed learning modules may integrate research which relates to the development of additional capacity in epilepsy unit nurses. Motivational interviewing skills, for example may assist

nurses to tailor care planning to promote engagement in follow up treatment for those with an exit diagnosis of PNES.

### **The Leadership Competency**

The leadership competency is evidenced by the identification of the learning needs of nurses in the diagnostic unit and work completed to develop a resource to assist with meeting these needs. Advocacy for an informed and prepared nursing staff to assist patients and families managing with the PNES which affect both their quality of life and health is also evidence of the Leadership Competency. The creation of the self-directed learning module is also demonstrative of a vision for how diagnostic unit nursing care and nursing relationships could be sensitive and supportive of the needs of needs of patients who have PNES or other mental health conditions. The leadership competency has been demonstrated by advocating for nurses to be better prior to engaging an unfamiliar patient. Leadership is also exhibited by acknowledging the presence of divisive and damaging attitudes in the nursing narrative and driving change in this context.

### **The Consultation and Collaboration Competency**

The Consultation was demonstrated through consultation with members of the larger healthcare system to effect change through the development of the learning module as quality improvement project. Additionally, the consultations have been the catalyst for access to a community which I had not previously been active. The healthcare professionals consulted offered or presented differing strengths, perspectives and

experiences all of which has relevance to the current project. Beyond the project, the consultations also allied previously detached teams. By connecting members of the community caring for people with PNES, the consultations have in a small way increased the collective social capital of the HCP community caring for people with PNES. Considering this was not a research project, the collaboration aspect of the competency will not be discussed.

### **Next Steps**

Completion of the self-directed PNES learning module for nurses signals an opportunity to integrate this resource into the current diagnostic epilepsy unit orientation which is categorically presently epilepsy-centric. Consolidation of the orientation educational material into a single more inclusive resource will greatly improve the level of preparation of nurses before accepting their first nursing assignment. The learning module has been designed and developed with integration to the hospital's online learning platform, *ilearn*. *ilearn* is an online learning interface which the hospital uses to assign learning activities to employees and has a standardized format which includes test or an evaluation component. *ilearn* affords the ability to mobilize the PNES learning module to other hospital programs which may also care for patients with PNES such as the emergency department or the intensive care unit. Another future activity would be to evaluate the impact of the PNES learning module in terms of a subjective measure of PNES preparedness. A possible future activity will be initiating contact with the Clinical Neurosciences program to discuss findings and develop a dissemination plan. By

comparing evaluation scores, a reissue of the learning module at one year following orientation could provide insight into the degree to which nurses have familiarized themselves with PNES and what it means to patients who have PNES. Developing a tool or mechanism for feedback is a very important and necessary next step. Solicitation of feedback from the diagnostic unit nurses, the experts consulted and nurses who have been exposed to the module in orientation will be an important source of suggestions for refinement or expansion.

### **Conclusion**

At end of the practicum, the objectives have been met. The environmental scan confirmed that there is a fractured healthcare landscape for individuals with PNES fraught with barriers. An in depth integrative literature review was conducted. Consultations with experts provided indispensable insight into the needs of nurses orienting to PNES as a legitimate medical condition as well as orienting to the diagnostic epilepsy unit. A context for nursing advocacy has been created by educating nurses of Clinical Neuroscience Program about the Mental Health Care Program. Advanced nursing practice competencies have been applied throughout the practicum and can be evidenced in the practicum objective end products.

From the outset, the practicum has been viewed as an opportunity to align academic preparation with my professional activities. Beyond an opportunity to marry two distinct spheres of my life, this practicum represented an opportunity to lead and deliver a direct positive contribution to the standard of nursing care provided to individuals who have



PNES. This practicum has driven purposeful critical reflection into my own understanding of the needs of PNES as a population health problem but also to challenge what has been considered acceptable standard of nursing care. The practicum required immersion in existing PNES-related knowledge and the context which surrounds providing nursing care in a diagnostic epilepsy unit to create a novel and necessary resource. The practicum project, the self-directed PNES learning module for nurses, is a well-rounded resource with corresponding application to a target audience and delivered to nurses at a specific time. The marriage of the learning module with the existing nursing orientation provides a more comprehensive approach to preparing nurses to engage an epilepsy unit population which has been undeclared and underserved.

This practicum has also been an opportunity to design and create a context for knowledge acquisition and application for all nurses. Advocacy using an evidence-informed approach to nursing care means to acknowledge, engage and then to transform. The opportunity to attempt to unveil the experience of the patient who will leave the epilepsy unit with an exit diagnosis of PNES has been an incredibly rewarding pursuit. Developing PNES literacy and competency new or inexperienced diagnostic unit nurses requires specialized and accessible educational resources. The self-directed PNES learning module for nurses champions the provision of individualized PNES nursing care whilst inspiring provider satisfaction and a quality patient experience.

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Psychogenic Non-Epileptic Seizures and Education  
for Nurses in Diagnostic Epilepsy Units:  
Integrative Literature Review

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## **Abstract**

Epilepsy diagnostic units are established hospital programs where people receive a diagnosis of psychogenic non-epileptic seizures (PNES). Unchecked, PNES have been demonstrated to have deleterious effects on the potential of individuals diagnosed with the condition. The healthcare professionals working in a diagnostic epilepsy unit play a particularly important role as it relates to PNES population outcomes. Engagement of the individual diagnosed with PNES requires the nursing team to utilize an approach to the nurse-patient relationship which is sensitive to the unique needs and coping response of these individuals. It is therefore of significant importance for the Epilepsy Program staff to appreciate their role in relation to the care provided to people with PNES. Education surrounding PNES is a strategic means to develop capacity in healthcare providers which fosters competence assisting this population during their hospitalization and transition to follow-up in the community. The principal intention is to promote the circumstances which validate quality healthcare practices for patients and families. It is of equal importance for the architects of any self-directed PNES health education module for nurses working in diagnostic epilepsy unit to be aware of the needs and attributes of adult learners, as well as the circumstances which promote the acquisition of knowledge in nurses.

## **Introduction**

While the presentation of psychogenic non-epileptic seizures (PNES) may be similar to those of epileptic seizures when expressed, PNES are however, not the result of excessive neuronal activity in the area known as the cerebral cortex of the affected person's brain. PNES can be characterized by involuntary discontinuous changes in behaviour, sensorium, consciousness and cognition which results in non-epileptiform seizure activity (Babiker, 2015). Precipitants to seizures in individuals diagnosed with PNES can be understood to be related to psychological distress or underlying psychopathology as opposed to having a neurological origin (Jones et al., 2010). Similar to epilepsy, non-epileptic seizures can be life altering and detrimental to global functioning (Gubbi et al., 2015). Current appreciation of both incidence and prevalence of PNES may be gross underestimations and by extension, misrepresentative of the scope of the population health problem. Incidence of PNES in the American general population is believed to be about 1.5/100,000 people. Epilepsy diagnostic units however report significantly higher incidence of about 5/100,000 per annum (Verrotti, Pavone, Agostinelli, Nanni & Gobbi, 2012; Karakis et al., 2014). PNES has been shown to positively correlate with increased co-morbid psychopathology, increased healthcare contacts, reliance on social assistance, polypharmacy, impaired cognitive and social functioning as well as effecting a significant economic burden on the healthcare system (Goldstein et al., 2011; Asadi-Pooya & Sperling, 2015; O'Brien, et al., 2015). PNES are pervasive and pernicious paroxysmal events which have serious implications for the individual and their loved ones, the

surrounding community and the healthcare system. PNES remains a poorly understood population health problem.

Diagnostic epilepsy units are where the diagnosis of PNES is often made or confirmed for individuals. The instance surrounding the provision of a PNES diagnosis to patients is understood to be a sensitive period or the decisive moment as it relates to an individual's motivation and prospective ability to cope (Karterud, Knizek & Nakken, 2011).

Diagnostic epilepsy unit nurses maintain a day and night relationship the in-patients and as a result may have more contact with the patients with PNES than any other healthcare team member. It is then principle to adjustment of the patient with PNES that the nursing staff provide care which meets the evolving needs. Nurses working in epilepsy diagnostic units must be able to meet the needs of their patients with PNES. It is therefore necessary to enrich providers by way of health education surrounding the social, psychological and medical health challenges to achieving quality in life for people with PNES (Jones et al., 2010; MacDonald, Hill, Phan, Fitzgerald & Seneviratne, 2012; O'Sullivan, Redwood, Hunt, McMahon & O'Sullivan, 2013). Therefore, educating nurses about PNES, these nurses may be more receptive to the experience and needs of the patients with PNES for whom they provide care. Educating nurses working in diagnostic epilepsy unit nurses may also be an effective means to frustrate the stigma, negative attitudes and misinformation which survives within the medical community surrounding PNES and hindering those who live with the condition (Perez et al., 2015; Pretorious & Sparrow, 2015). Health education for diagnostic epilepsy nurses relating to PNES and the provision needs-based care to these patients as an imperative may also lend itself to an



understanding of the associated outcomes. Examples include: failing to provide resources, health teaching or advocating for contacts with appropriate care providers.

Health education programming acts as the nexus between improved outcomes for patients with PNES in epilepsy diagnostic units and PNES knowledge acquisition in the nurses which practice in the unit. The goal of this integrated literature review is to isolate the emergent themes present in the literature relating to PNES and electronic delivery of health education to nurses. This integrated literature review will inform the development of a self-directed PNES health education module for nurses in a diagnostic epilepsy unit.

All searches provided no results for articles which discussed PNES teaching materials for nursing staff working in diagnostic epilepsy units. The search strategy was modified to return results relating to PNES and a second search to return results for nursing and electronic learning. Literature which composed this review was sourced from the CINAHL, PubMed and MEDLINE data bases and included the Cochrane Library. Searches were initially limited to five years but due to a lack of viable results, the temporal search limitation was extended to include publications extended to 2005 to present for PNES nursing education. The search was further limited to the English language and journal articles published in academic journals. Search keywords included 'PNES', 'seizure', 'non-epileptic', 'nursing education', 'epilepsy e-learning'. The search returned 86 results. Results which related to semiology and diagnostic criteria for PNES were excluded on the basis of irrelevancy. Sixty three results were selected for inclusion

and compose the body of literature reviewed. The results of the search suggest a paucity in the literature as it relates to PNES modules or tools for nursing health education.

The review of literature results relating to PNES yielded three key themes which have relevance for nurses engaging patients with PNES in a diagnostic epilepsy unit. Emergent themes from the integrative literature review were: (1) life experiences of people living with PNES, (2) coping strategies typified by people with PNES and (3) the approach of healthcare providers in relation to PNES care provision. This integrative literature review will expound upon these themes. In addition, it will specifically inform how nursing care in a diagnostic epilepsy unit can help patients to adjust to their diagnosis and to assist in the preparation of these patients for the next step in their care journey.

### **Life Experience of People with PNES**

Living with PNES means living with stress, risk, angst and vulnerability. PNES are life altering paroxysmal events which have wide sweeping implications for people who experience or live with the symptoms. PNES stems from factors associated with an individual's biology or psychology as opposed to being the result of excessive and unrequited neuronal activity. This also serves as the basis for contrast between PNES and epilepsy (Pillai, Haut & Masur, 2015). PNES is understood to be the result of ineffective coping in response to stressors (Rawat, Dhinman, Sinha, Sagar & Thippeswamy, 2015). Stressors, in isolation or in combination, which populate the individual's environment, psychology, biology or psychosocial domains may precipitate seizure activity in those with a predisposition for responding to stress by seizing (Turner et al., 2011; Kanner et

al., 2013; Kaplan et al., 2013; Elliot & Charyton, 2014; Gubbi et al., 2015; Pillai, Haut & Masur, 2015). People with PNES often demonstrate impaired emotional processing of sensory information which can result in misattribution and overcompensation as the individual seeks stasis or relieve from the stressors. This can further worsen attempts to cope with stress (Uliaszek, Prensky & Baslet, 2012; van der Kruijs, Jagannathan, Bodde, Besseling & Lazeron, 2014; Navakova, Howlett, Baker & Reuber, 2015). Exposure to stressors and the means by which an individual's respond to stress plays a central role to the expression of PNES.

Physical and sexual trauma is very common amongst people with PNES which may also have a compounding relationship with impaired emotional processing and the characteristic ineffective or maladaptive coping (Kaplan et al., 2013; Say, Tasdemir, Akbas, Yüce & Karabekiroglu, 2014; Barzegaran, Carmeli, Rossetti, Frackowiak & Knyazeva, 2015; Wichaidit, Ostergaard & Rask, 2015). Psychiatric illness and psychological deficits are very much associated with PNES and will also emerge longitudinally as additional stressors which may promote seizure activity in those with the predisposition (Patidar et al., 2013; Duncan et al., 2014; Say, Tasdemir, Akbas, Yüce & Karabekiroglu, 2014; Beghi et al., 2015; Pillai, Haut, Masur, 2015; Rawat, Dhinman, Sinha, Sagar & Thippeswamy, 2015). Anxiety, in particular is very likely to present in individuals with PNES causing isolation or deleteriously affecting the functioning of the individual (Patidar et al., 2013; Dhiman et al., 2014; Elliot & Charyton, 2014; Hendrickson, Popescu, Dixit, Ghearing & Bagic, 2014; Beghi et al., 2015). In addition to caregiver burnout, PNES is also associated with interpersonal conflict of parental and

spousal relationships suggesting PNES has a wide sphere of influence as it relates to social functioning (Meyers, Lancman, Laban-Grant, Matzner & Lancman, 2012; Karakis et al., 2014; Say, Tasdemir, Akbas, Yüce & Karabekiroglu, 2014). By administering the of tools such as the Minnesota Multiphasic Personality Inventory (MMPI), State Trait Anger Expression Inventory -2 and Quality of Life in Epilepsy-31 as part of a neurocognitive and psychological battery to a sample of patients diagnosed with PNES (n=62) drawn consecutively from an Northeastern American diagnostic unit, Meyers, Lancman, Laban-Grant, Matzner & Lancman (2012) demonstrated a relationship between PNES low quality of life, depression and inappropriate anger expression as a root cause of interpersonal conflict. People who experience PNES often have academic difficulties, challenges maintaining employment, tendency to rely on social assistance and frequently access healthcare resources (Bodde et al., 2013; Duncan et al., 2014; Say, Tasdemir, Akbas, Yüce & Karabekiroglu, 2014; Rawat, Dhinman, Sinha, Sagar & Thippeswamy, 2015). While living with PNES is demanding on its own, there is a constellation of various internal and external stressors that generate circumstances which can be challenging for an individual to manage alone.

People seeking help with PNES experience challenges accessing specialized care (Pretorius & Sparrow, 2015). PNES are frequently diagnosed as intractable epilepsy and as a result, patients presenting with non-epileptic seizures may be prescribed antiepileptic medications which can be harmful and may result in further healthcare utilization (O'Sullivan, Redwood, Hunt, McMahon and O'Sullivan, 2013; Duncan et al., 2014; Santos, Benute, Santiago, Marchiori & Lucia, 2014). Whether an inpatient or a member

of the community, people with PNES are at a greater risk for physical injuries, unpredictable seizure activity and discomfiting results, such as, urinary incontinence which may lead to isolative behaviours in some individuals making access to specialized health care that much more unattainable (Asadi-Pooya, Emami & Emami, 2014). When access to specialized care is made available or otherwise achieved, interventions have demonstrated to improve severity and frequency of seizures, decreased healthcare utilization. Self-reported measures on quality of life, however, do not improve despite reduced seizure activity (Mayor et al., 2012). The lack of congruence between objective health measures and quality of life measures may suggest a relationship with impaired emotional processing or misattribution of significance to the health condition create implications for other facets or aspects in the individual's life. Furthermore, the lack of improvement in self-perceived quality of life measures also implies that for the individual, PNES are the expression of single or multiple underlying pathologies working in concert with ineffective internal processes which may not completely resolve when there is a cessation of seizure activity.

A subtheme which emerged from the literature is psychological distress as a life experience for people with PNES. PNES have been described as a manifestation of underlying psychological distress (Novakova, Howlett, Baker & Reuber, 2015).

Psychological distress can be understood to be ineffectual cognitive processes which produce responses such as, somatic complaints, depression or anxiety which subsequently have a role in eliciting defense mechanisms producing PNES (Beghi et al., 2015; Gubbi et al., 2015). Impaired emotional processing is strongly correlated with psychological

distress. This can result in a damaging interpretations and misattribution of symptoms which emerge in response to or precipitate PNES (Novakova, Howlett, Baker & Reuber, 2015). Impaired social functioning secondary to psychological distress has been associated with increased interpersonal conflict which has a relationship with anxiety, depression and decreased quality of life in people with PNES (Myers, Lancman, Laban-Grant, Matzner & Lancman, 2012; Hendrickson, Popescu, Dixit, Ghering & Bagic, 2012); Say, Tasdemir, Akbas, Yüce & Karabekiroglu, 2014). Psychological distress may act as a precipitant of or emerge in response to both predictable and capricious elements associated with PNES. These elements can develop and potentiate a negative feedback loop which further exacerbates a hard-hitting individual context.

### **Coping Strategies of People with PNES**

Coping with PNES and the constellation of associated difficulties can be understood to be an individual's attempt to manage the circumstances which emerge from the interaction of these variables. For people with PNES, attempts to cope often involve the use of defense mechanisms which tend to be ineffective and deleterious in relation to global functioning (Beghi et al., 2015). Coping strategies are typified by avoidance, suppression and impoverished emotional experiences (Novakova, Howlett, Baker & Reuber, 2015). Emotion-driven behaviours and avoidance are characteristic strategies employed by people with PNES to cope (Acton & Tatum, 2013; Meyers, Fleming, Lancman, Perrine & Lancman, 2013). From a sample of American men and woman diagnosed with PNES (n=82) Meyers, Fleming, Lancman, Perrine & Lancman (2013)

demonstrated that avoidance ( $p=0.005$ ) and emotion-oriented behaviour ( $p=0.001$ ) were preferential coping strategies which emphasizes the maladaptive response to stress in this population. Using ANOVA to compare T scores between coping strategies, Pearson product-moment correlation to measure the association between neuropsychological tools (TAS-20, TSI 2, STAXI-2 and MMPI-2- RF) and stepwise liner regression to determine significance, Meyers, Fleming, Lancman, Perrine & Lancman demonstrated a gross under-utilization of task-oriented coping strategies. Not surprisingly, when compared to a normative sample, these researchers found 61% of people with PNES will select a coping strategy which is one and half standard deviations away from the mean.

Ineffective coping can be pathological and can have unhealthy consequences for people with PNES. In this context psychopathology leads to ineffective coping which leads to psychopathology which leads to ineffective coping and so on (Uliaszek, Prensky & Baslet, 2012; Myers, Fleming, Lancman, Perrine & Lancman, 2013; Novakova Howlett, Baker & Reuber, 2015). When an individual attempts to cope with PNES are ineffective, Meyers Lancman, Laban-Grant, Matzner & Lancman (2012) articulated a relationship between these attempts with emotional dysregulation ( $p<0.0001$ ), severe psychiatric symptoms ( $p<0.001$ ), impaired quality of life ( $p<0.003$ ) emotional unawareness ( $p<0.05$ ) and avoidant ( $p=0.001$ ) behaviours. This study was comprised of 62 consecutively enrolled diagnostic unit patients who had video-EEG confirmation of PNES is remarkable for the suggestion that with in PNES, anger expression and cynicism are key influences on the effectiveness of selected coping strategies but are also the mediators of perceived quality of life in this population. Coping with PNES can elicit

additional challenges. If the individual selects an inappropriate strategy, this response can inflame circumstances significantly and possibly present new stressors for the individual to negotiate with a coping response.

People with PNES attempt to cope with their seizures by presenting to healthcare providers to help obtain a healthcare response. Presenting to healthcare as a means to cope can provide access to care, medication and monies which can be advantageous as it relates to global health for those who have PNES (Duncan et al., 2014; Novakova, Howlett, Baker & Reuber, 2015). Seeking help from healthcare providers may not always be beneficial for people with PNES and in many cases can prolong the ruinous conditions which often surround untreated PNES (Pretorius & Sparrow, 2015). For example, presenting to the emergency room with PNES may result in the wrong treatment path which is owed to the considerable variation in neurological experience of emergency physicians who may be unfamiliar with PNES, or specialized diagnostic epilepsy units where epilepsy can be ruled out (O'Sullivan, Redwood, Hunt, McMahon & O'Sullivan, 2012). Despite a limited sample size, a time-bound cohort study of consecutively enrolled patients (n=63; 90% female) diagnosed with PNES in an Indian diagnostic unit, Patidar et al., (2013) found a very high degree of suspicion of PNES is required to refer someone for diagnosis which underscores the knowledge of both PNES and diagnostic units. Unfortunately, this study also found 44% of patients eventually diagnosed with PNES have been prescribed antiepileptic medications which were at best ineffective and at worst a dangerous intervention.



Individuals who have been placed on an incorrect treatment path by way of an incorrect medical diagnosis are likely to be exposed to antiepileptic medications which can be very harmful pharmacological agents (Kanner et al., 2012; Santos et al., 2014; Duncan et al., 2014). Motivation as well as the initial patient experience upon presentation for healthcare can influence subsequent events. However, it can also offer insight into the role of nursing's relationship with this population. Researchers Baxter et al., (2013) completed an exploratory qualitative inquiry into the patient (n=12) perspective leading to and upon diagnosis of PNES. Six important themes were identified: (1) Getting answers (2) Vulnerability (3) Seeking a physiological explanation (4) Doubting the diagnosis of PNES (5) The role of medication in relation to PNES and (6) Finding a way forward. Noteworthy is four of these six themes can be associated with avoidant coping styles which suggests that coping strategies employed by people with PNES remains intact despite engagement with healthcare professionals. Family and loved ones provide crucial support to the individual in many ways, but are also central to successful healthcare interventions for PNES. If family/loved ones are not engaged when patients diagnosed with PNES when referred to mental health care as part of a divided intervention, patients will generally avoid and not be adherent to follow-up care. In this case, avoidance implies that the patient is likely to persist with ineffective coping strategies or maintain ambivalence toward the condition (Baslet & Prensky, 2013). However when, patients with PNES are offered psychiatric consultation during their admission to an epilepsy diagnostic unit, patients are much less likely to refuse this

contact. This suggests avoidance may be contextual, associated with and interrupted care chronology or divided interventions (Acton & Tatum, 2013; Baslet & Prensky, 2013).

People who experience PNES appear to be ‘hardwired’ for an ineffective coping response which connects the internal to the external, cognition to emotion whilst producing context for the associated psychological distress in which the coping response is expressed as seizure activity (van der Kruijs et al., 2012; Meyers, Lancman, Laban-Grant, Matzner & Lancman, 2012; Meyers, Fleming, Lancman, Perrine & Lancman, 2013; Elliot & Charyton, 2014; Novakova, Howlett, Baker & Reuber, 2015). This confluence of circumstance as it relates to a person with PNES is of primary importance to healthcare providers seeking to engage a patient, understand their presentation and in deed, help the person to cope with life.

### **The Role of Healthcare Providers**

Healthcare providers (HCPs) are positioned along the healthcare continuum to assist individuals and families to restore health and balance in healthcare situations. HCPs can also guide and direct patients through their healthcare journey whilst possessing tremendous influence over the direction and trajectory of specific and future healthcare encounters. These healthcare encounters can be advantageous for the patient or they can be detrimental. Emergent from the literature is a triad of themes relating to the role of HCPs: 1) Access to care 2) Barriers to care and 3) The approach of the healthcare team. Truly, it is the outcomes of a person with PNES who has presented for health care

which can be influenced depending on the how and by whom health care is delivered to them.

Persons with PNES visit to healthcare institutions, programs and professionals for support, information and therapeutics (Santos et al., 2014; Duncan et al., 2015; Gubbi et al., 2015; Pretorius & Sparrow, 2015). When HCPs provide access to appropriate specialized care for PNES, outcomes are very favourable in relation to baseline seizure occurrence and healthcare utilization (Mayor et al., 2012; Martlew, Pulman and Marson, 2014; Santos et al., 2014). Also, in situations where healthcare for the individual is managed correctly, PNES can resolve and patients can remain seizure-free following individualized intervention (Mayor et al., 2012; Patidar et al., 2013; Rawat, Dhinman, Sinha, Sagar & Thippeswamy, 2015). Favourable outcomes have the potential to begin in the emergency room of hospitals when people with PNES present seeking collaboration with HCPs. When emergency department health care teams refer to specialized diagnostic units or tertiary care programs, the seizures of people with PNES are significantly more likely to be correctly identified as PNES ( $p < 0.0005$ ), which reduces exposures to antiepileptic agents and promotes an improved individual and caregiver experience with non-epileptic seizure expression (O'Sullivan, Redwood, Hunt, McMahon & O'Sullivan, 2013; Karakis et al., 2014; Duncan et al., 2015). Once the diagnosis of PNES is made, access to specialized care for those who engage in treatment has demonstrated to promote very favourable outcomes in relation to emotional and somatic well-being, quality of interpersonal relationships, healthcare utilization and seizure frequency (Kanner et al., 2012; Mayor et al., 2012; Myers, Lancman, Laban-Grant,

Matzner & Lancman, 2012; Duncan et al., 2014; Santos, Benute, Santiago, Marchiori & Lucia, 2014). Case by case assessment of need ensures that individuals who require acute intervention have access to specialized care but also requires an inter-programmatic collaborative between neurology epilepsy diagnostic units and mental health to validate said access to specialized care (Acton & Tatum, 2013; Dhiman et al., 2014; Santos, Benute, Santiago, Marchiori & Lucia, 2014). People presenting to HPCs with seizure activity require specialized diagnostics to determine the origin of the seizures. Once determined to be PNES, patients require access to specialized medical care to assist with healing and recovering from the underlying precipitants as they relate to the seizures.

While access to specialized diagnostic and medical care are favour improved outcomes for people experiencing PNES, seeking a healthcare intervention is not always helpful and in some cases can be detrimental. Healthcare providers control access to specialized help, resources or support while inexperienced providers at healthcare entry points may not afford access despite best intentions (O’Sullivan, Redwood, Hunt, McMahon & O’Sullivan, 2013; Santos et al., 2014; Pretorius & Sparrow, 2015). When physicians at healthcare entry points, such as emergency rooms or in family practices, are ill informed or lack knowledge in relation to neurology or specifically PNES, misdiagnosis often occurs (Patidar, 2013; Duncan et al., 2014; Santos, Benute, Santiago, Marchiori & Lucia, 2014; Yates, 2014). Misdiagnosis can be very costly for people experiencing PNES. Codified diagnostic manuals which provide criteria for diagnosis of PNES, such as the American Psychiatric Association *Diagnostic and Statistical Manual of Mental Disorders* (2013) or the World Health Organization *International*

*Classification of Diseases* (2015), do not share common language in relation to PNES and may contribute to confusion or uncertainty when formulating care plans (Yates, 2014; Beghi et al., 2015; Brigo et al., 2015; Wichaidit, Ostergaard & Rask, 2015). Whether diagnosed as intractable epilepsy or other, misdiagnosis can unnecessarily expose people to antiepileptic medications, associated pharmacological pathogenic sequelae and delaying correct diagnosis by several years for some patients (Bodde et al., 2012; Kanner et al., 2012; Ahmedani et al., 2013; Dhiman et al., 2014; Gubbi et al., 2015). Perhaps the greatest barrier to people seeking healthcare for PNES are healthcare providers. Conceivably more damaging than inexperience, negative attitudes and stigma in relation to PNES which lives within healthcare teams and amongst providers (Pretorius & Sparrow, 2015). Negative attribution to PNES, such as ‘fake’, attention seeking or the seizures being under volitional control, is very common amongst nurses which may influence interpersonal nursing dynamics and quality of nursing care (Sahaya, Dholakia, Lardizabal & Sahota, 2012). While instrumental to formal interventions for PNES, healthcare providers can also be a barrier to care, treatment and resolution. Beyond this, healthcare providers may in fact, prolong time to diagnosis, control access to specialized diagnostic and medical care for people with PNES while exposing individuals to detrimental pharmacological agents.

Access and barriers to care are themes which emerge from the literature as it relates to PNES outcome. Engagement of an individual and family by a specialized team is also of primary importance to these same outcomes. The approach of a healthcare team in this regard relates to how or the means by which the person with PNES is engaged in a

healthcare relationship. Responding to the healthcare needs of people presenting with non-epileptic seizures requires a multidisciplinary and inter programmatic collaboration to achieve ends which do not occur outside of divided interventions (Duncan et al., 2015; Beghi et al., 2015; Pretorius and Sparrow, 2015; Rawat, Dhinman, Sinha, Sagar & Thippeswamy, 2015). A biopsychosocial orientation to the diagnosis and treatment of PNES seeks to address the precipitants to the seizures (Elliot & Charyton, 2014). When the healthcare providers appreciate that PNES are not seizures in isolation, the approach of team is then cognizant of the potential for impaired information processing and will include assessment of stress, mood, coping style and social functioning (Myers, Fleming, Lancman Perrine & Lancman, 2013; Myers, Lancman, Perrine & Lancman, 2013; Novakova, Howlett, Baker & Reuber, 2015; Rawat, Dhinman, Sinah, Sagar & Thippeswamy, 2015). Approaching PNES with a tailored care plan for the individual anticipates avoidance and impaired emotion regulation as a characteristic of the population as opposed to labeling the coping response as indifference, disengagement or refusal (Baxter et al., 2012; Meyers, Fleming, Lancman, Perrine & Lancman, 2013; Wichaidit, Ostergaard & Rask, 2015). A patient and family-centric approach to healthcare of the individual with PNES is considerate of the burden which PNES places on caregivers and loved ones but, also primes these supports for participation the care plan (Karakis et al., 2014; Say, Tasdemir, Akbas, Yüce & Karabekiroglu, 2014). Unfortunately, the capacity to meet the healthcare needs of people presenting with PNES to medical professionals is underdeveloped in many hospital programs.

Proficiency in care provision and sensitivity to PNES and the experience of the people who experience non epileptic seizures within a healthcare team needs to be developed through targeted education before the enhanced approach of the team can be integrated into practice (MacDonald, Hill, Phan, Fitzgerald & Seneviratne, 2012; O'Sullivan, Redwood, Hunt, McMahon & O'Sullivan, 2013). Employing a model of care which attends to the underlying cause of the seizures requires a multidisciplinary approach to engaging the individual and may require an inter-programmatic collaborative to answer the derivation of PNES. Team based healthcare provision requires for healthcare providers to not focus on the expression of the seizure but, to be deliberate in spotlighting the factors which produce seizures through collaboration with other providers and specialties as a means to break the seizure producing cycle. Breaking the seizure producing cycle requires a conscientious approach to people presenting with PNES and this awareness can be cultivated in a team or provider through education.

### **Nursing and Knowledge Acquisition**

As was discovered in the search for PNES education material for nurses, no literature was found for studies which focused specifically on how to teach nurses working in diagnostic epilepsy units about PNES. The search did return results which have been organized into three central themes: (1) Impact of e-learning on nurses, (2). PNES training and (3) epilepsy-based e-learning for nurses. These three themes will be discussed as major headings and will inform the examination of PNES and how nursing education can support practice improvement and PNES population literacy in nurses.

## **Impact of e-Learning on Nurses**

The Canadian Nurses Association declares it is only through education that nurses can meet the demands of contemporary healthcare practice environments (Canadian Nurses Association, 2016). Technology enabled delivery of education, or e-learning, has become a common mode of instruction in the education of nurses and nursing students. Nursing has endorsed the utilization of e-learning as a flexible and convenient means to educate nurses and nursing students in the provision of both basic and post-basic education (Button, Harrington & Belan, 2014; Lahti, Hatonen & Valimaki, 2014; Liu, Chu & Chen, 2014; Liu, Rong & Liu, 2014). E-learning has been demonstrated to be an effective method to improving knowledge and skill enhancement in nurses (Bloomfield, While & Roberts, 2008; Du et al., 2013; Petty, 2013; McCutcheon, Lohan, Traynor & Martin, 2015). Engaging nurses in e-learning opportunities is also associated with increasing self-efficacious behaviours and confidence in nursing practice (Sahaya, Dholakia, Lardizabal & Sahota, 2012; McCutcheon, Lohan, Traynor & Martin, 2015). When contrasted with traditional nursing education methods such as lectures and textbooks, e-learning is considered to be at least as effective as these methods and may have some additional benefits for learners as well (Roh & Park, 2010; Feng et al., 2013; Lahti, Hatonen & Valimaki, 2014). Affording the recipient an accommodating and interactive style of delivery, e-learning is positively correlated with increased satisfaction as it relates to more traditional methods of nursing education (Du et al., 2013; Petty, 2013; Lahti, Hatonen & Valimaki, 2014; Liu, Rong & Liu, 2014).



While generally an effective teaching method for nurses, e-learning can be inaccessible or cumbersome for nurses who do not possess a degree of computer literacy or have a learning style which is not receptive to e-learning (Petty, 2013). Further to this end, situated and virtual learning have a significant effect on student nurses' knowledge acquisition and skill performance in student and novice nurses but not in experienced nurses. This suggest the effectiveness of these forms of e-learning may be associated with the novelty of the exposure or poor adaptability to an established nursing practice (De Gagne, Oh, Kang, Vorderstrasse & Johnson, 2013; Feng et al., 2013; Dworetzky et al., 2015). E-learning has been demonstrated to be effective when tailored and adapted to diverse nursing practice environments and settings including epilepsy monitoring units (Locharernkul, Suwaroporn, Krongthong, Limarun & Arnamwong, 2010; Stecker & Stecker, 2012; Dwortezky et al., 2015). Technology enabled teaching methods are effective alternatives to traditional means of educating nurses. E-learning offers elements of convenience and a satisfying educational experience while maintaining effectiveness as it relates to knowledge acquisition, confidence integrating learning into practice and promoting self-efficacy amongst nurses. While it is acknowledged that e-learning will not appeal to all nurses, it is an accepted and effective means to educate student and experienced nurses.

### **Psychogenic Non-Epileptic Seizure Education**

Preparing nurses to engage people who experience PNES requires the provision of education surrounding the health condition and the experience of people who live with

or in proximity to the seizures. Education specific to PNES is central to assisting nurses to effectively respond the unique needs and coping styles of people presenting with PNES to (or have already been) engaged in the healthcare system (Sahaya, Dhloakia, Lardizabal & Sahota, 2012; Yates, 2014). When nurses in epilepsy monitoring units are exposed to education relating to epileptic seizure identification, translation to practice takes place. It is also through education that nurse practice enhancements are sustained into follow-up and future nursing situations (Isler et al., 2008; Lochareernkul, Suwaroporn, Krongthong, Limarun & Arnamwong, 2010; Stecker & Stecker, 2012). There is promise that these results can be translated into PNES education. Nurses who have been exposed to electronically delivered education surrounding recognition of epileptic seizures are reliably able to translate the information into correct identification of epileptic seizures with the effect of the education also being sustained post-intervention into follow-up (Mayor et al., 2013; De Paola et al., 2016). Nurses working in diagnostic epilepsy units have the ability to receive education surrounding seizures and integrate the information into practice. It also suggests nurses can modify practice to accommodate information which helps them to better care for the patients of the epilepsy unit. This may include initial specialized healthcare contact of patients experiencing PNES (Isler et al., 2008; Stecker & Stecker, 2013; Mayor et al., 2013; DePaola et al., 2016). Nurses in the employ of a diagnostic epilepsy unit can adapt routine practice to accommodate new information or build upon requisite knowledge which makes the provision of PNES education a promising opportunity to build an appreciation for what contributes to the expression of a PNES. Once an appreciation for the precipitants to

PNES is developed within the nursing staff, the potential is there to engage people who experience PNES. Nursing practice and the individual are interconnected during the admission and prior to discharge where there is a unique potential to alter the trajectory of the condition is present.

### **Theoretical Framework**

The current review of PNES literature is augmented by a complementary review of literature which comments on the tenants of adult learning, characteristics of adult learners and conditions which promote learning in nurses. This section will discuss Knowles (1984) Theory of Adult Learners, Kolb (1974) Theory of Experiential Learning theory of experimental learning and learning style inventory is related to the Benner's (1984) description of the progression from novice to expert. The contribution from these bodies of work will be synthesized into an amalgam support the creation of a self-directed PNES learning module for nurses working in diagnostic epilepsy units.

### **Knowles' Theory of Adult Learner**

In contrast with classical pedagogy, andragogy is a learner as opposed to a teacher-centered conceptualization of how and why adult learners learn which also has implications for how adult learners can be motivated to receive instruction. Andragogy is characterized by an emphasis on the teacher facilitating the acquisition of knowledge in the adult learner by using an approach which draws upon the learner's prior knowledge to

challenge ideas or problems or to integrate new concepts into one's schema (Yates, J., 2014). A forerunner in the development of Adult Learning Theory was the work of Malcom Knowles who introduced six core principles to organize the assumptions surrounding the instruction of adult learners (Norrie & Dalby, 2007; Clapper, 2010).

These six principles proposed in Knowles' theory of adult learning assumes:

- i. If adult learners are made aware of why learning is relevant or the pragmatic value revealed, they will be more motivated to learn.
- ii. If an adult learner's experience is valued, it is integrated into learning as a resource for learning which can motivate adult learners to engage in a learning opportunity.
- iii. Adult learners are autonomous and independent, capable of engaging in self-directed learning and must assume accountability for their own learning.
- iv. Teachers are stewards of the adult learner's internal motivation to continue learning and adult learners can remain engaged by adhering to adult learning principles.
- v. Adult learners become motivated to learn when the education has utility and pragmatic value to them personally (e.g. PNES education for nurses working with people experiencing psychogenic seizures in a diagnostic epilepsy unit).
- vi. When learning opportunities and knowledge can be extracted from 'real-world' events or problems, the learning can be more effective and leveraged as the rationale for a change in clinical nursing practice for example.

By engaging the experience and knowledge which adult learners possess, an andragogical teacher or the architect of a learning module is mindful of the shared experience of education. The acknowledgement of knowledge acquisition in the adult learner is very much about adding context to content.

### **Kolb's Experiential Learning Theory and Learning Style Inventory.**

Complementing the work of Knowles, Kolb's abstractions of adult learning also acknowledges experience as a resource for learning and participation the means to learning. The experience of learning has a crucial influence on the learning process for adult learners. In his theory of experiential learning, Kolb presented a cyclical construct of adult learning which consists of four distinct stages each underscoring the "essentiality of practical experience to the learner's knowledge development" (Cooley & De Gagnon, 2016, p. 97). The stages of articulated by Kolb's Experiential Learning Theory include:

- i. Concrete experience through immersion which suggests the means to learning is active participation.
- ii. Reflective observation demands for the learner to remove themselves from active participation and critically review the experience by asking questions and making connections.
- iii. Abstract conceptualization is a method for making sense of experience and learning by making connections, challenging what is already known through the

interpretation and integration of new ideas or information into (or contrasting with) the existing schema.

- iv. Active experimentation involves deploying new learning into practice or use.

Active experimentation affords the learner the ability to make predictions and to refine, revise and realize outcomes associated with the acquisition of knowledge.

These stages are cyclical and lead to restarting or a regeneration of the cycle. Through the continuation of this cycle through the advancement and acquisition of new knowledge, the adult learner is continuously testing and integrating knowledge which in turn informs experience through learning (Lai, Lee, Chui & Shih-Tsang, 2014). Experiential learning involves active participation in learning opportunities and for nurses; this means integrating and experimenting with a newly acquired skill or understanding in clinical practice.

Kolb identified four associated learning styles in which learners can be characterized by the means in which adult learners best acquire knowledge. Kolb suggested that learners can use multiple approaches to acquiring knowledge, but are likely to rely upon a dominate or preferred style of learning (Hosseini, Amery, Emadzadeh & Babazadeh, 2015). Kolb's learning style inventory emanates from experiential learning theory as Lai, Lee, Chiu & Shih-Tsang (2014) explain, the learning style inventory categories are inclusive of:

- i. Accommodating learning style favours an immersive hands-on experience which involves the use of perception and awareness, as opposed to a logical strategy for discovery and learning.
- ii. Assimilating learning style is preferred by adult learners who are detail-oriented and logical in how new information is acquired and integrated. People who favour the assimilating style of learning require learning opportunities which offer stepwise organization of themes and appreciate an opportunity to reflect upon information.
- iii. Convergent learning style is preferred by adult learners who tend to easily translate theoretical or technical information into an understanding which has application to a problem or a practical use.
- iv. Divergent learning style is employed by those who are moved viscerally by experience and can channel this emotive power into discovery. Divergent learners seek to acquire and consider multiple views on a situation or idea as a vehicle of understanding and adaptation.

Exploring and understanding adult learning styles from the perspective of Kolb's stages of learning, will serve to clarify the design of a health education learning module and present an opportunity to engage the adult learner in professional growth (Williams, Brown & Etherington, 2012). When Kolb's stages of learning are paired with an appreciation of learning style, learning can be tailored and made accessible to people with a particular predisposition to acquiring knowledge, as well as influencing motivation to continue learning. In relation to learning module design, it will be important to consider

the potential for all learning styles to be present in the membership of the unit's nursing staff.

### **Benner's Description of Clinical Competence: Novice to Expert**

Benner (1982) described a series of stations which nurses pass through as they acquire knowledge and gain experience moving through five levels of nursing proficiency marking the transition from novice to expert. The description provided by Benner in relation to the progression of a nurse from novice to expert is representative of a fluid gating framework which permits advancement as mastery of nursing practice develops. The acquisition of nursing education and skills to be integrated or honed by nursing practice serves as the means by which nurses advance from novice to expert. Nurses serially advance through five gates by developing nursing proficiency as described by Benner consisting of:

- i. Novice nurses are largely naïve to nursing practice and are capable of engaging in task oriented work which is structured by objective measures and obvious indicators of succession or completion
- ii. Advanced Beginner nurses have acquired exposure to nursing practice and have begun to develop a collection of nursing experiences from which the advance beginner can start to recognize patterns or compare features of the outcomes of nursing exchanges. Nursing judgment of non-objective measures is limited to comparisons prior exposures to patients with similar presentations.



- iii. Competent nurses have developed proficiency from several years of nursing experience and acquiring nursing knowledge. As opposed to being driven by stimulus or fear of exposure, nursing actions are increasingly more deliberate and purposed to become aligned with increasingly longitudinal outcomes or patient care goals.
- iv. Proficient nurses are typified by an increasing holistic view of patient and the healthcare system in which they are immersed. Proficiency in practice is typified by the nurse being able to rely on experience to isolate classic elements of a patient care situation, the importance of specific nursing actions relative to outcome and a tolerance for values outside of normative ranges.
- v. Expert nursing is obvious when observed yet difficult to describe. Expert nurses have an extensive accumulation of experiences arising from countless interactions and exchanges as a nursing provider and nursing professional. Expert nurses are intimately comfortable with their practice environment and have earned self-assurance as it relates the ability to rely on impressions and intuition to guide nursing actions or nursing influence to control patient care situations. The perspective of the expert nurse has broadened beyond direct patient care matters to systemic, professional or policy related matters which are nursing forums where experience and expertise have tangible currency, mass and weight.

A criticism of the novice to expert description put forward by Benner is that nursing practice can be learned; it cannot be taught to the individual. This suggests that advancing beyond novice requires predominantly the accumulation of formative experience via

nursing practice (Gardner, 2012). Further to this end, progression through the novice-to-expert stations may not be wholly driven by nursing experience or engagement in nursing activities. In their work surrounding the ‘perpetual novice’ Wilson, Harwood and Oudshoorn (2015) argue that factors external to the nurse possess significant influence and determination as to whether or how nurses progress from novice status. These factors include working night shifts, a disapproving nursing unit culture, absence of a nurse educator attached to the hospital program and an increasing nursing workload. The ability of a nurse to progress through the novice to expert strata has a clear relationship with internal and external factors driven by experience and context. Internal factors and the influence of factors outside of the nurse can work in isolation or in concert as facilitative features or act as barriers to advancing proficiency in nursing practice.

Adult learning, when paired with consideration for individual learning styles, as well as the conditions in which nursing proficiency is cultivated, both participation and experience emerge as central themes. As it relates to nursing education, learning and development as a nurse, participatory exposure leads to meaningful experience. Participation and experience are intertwined and inseparable elements of expertise and competence. These elements are crucial to the advancement of nursing practice. Adult learners bring with them a repertoire of valuable experiences and it is through integrating the requisite experience that motivation can be influenced promoting the potential to acquire additional learnings. Through acquisition and application of experience, a nurse can translate experience into nursing practice as a viable means to promote and develop nursing proficiency.

Psychogenic non-epileptic seizures are pervasive, pernicious and can have a significant and often deleterious influence on both an individual and those in proximity to the seizures. A constellation of underlying psychopathological conditions and circumstances producing non-epileptiform seizure activity often act as barriers to achieving quality in life for those with the predisposition. The diagnosis of PNES should signal a new beginning or pathway for both patients and healthcare providers. For many patients, the antecedent to discharge from the epilepsy program is the diagnosis of PNES. Providing quality support and healthcare options to those diagnosed with PNES prior to discharge while these individuals remain inpatients of the unit. The provision of support and tailored healthcare interventions must precede and accompany the discharge order if the deleterious consequences associated with PNES sequelae are to be mitigated or avoided. This standard of care will remain unattainable if healthcare providers are not informed of the individual and societal challenges PNES will have for the patients leaving the diagnostic unit. Perhaps more valuable still may be reinforcing the epilepsy diagnostic unit's role in improving outcomes for people with PNES via influencing the trajectory of this devastating condition.

Development of a self-directed PNES health education module for nurses of diagnostic epilepsy units is not only supported by the literature, but appears to be the principle means to improve the healthcare experience of patients with PNES while in the care of the Epilepsy Program. The review of literature surrounding PNES articulates the presence of a need to better serve this patient population. Education is a principal means to enhance nursing practice which includes specific exposure to seizure education. Taken as

a whole, the literature supports the development of a much needed self-directed PNES learning module for nurses working with people who have PNES especially those nurses working in a diagnostic epilepsy unit.

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## Literature Summary Tables

Citation and Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths / and Limitations	Conclusion and Rating
<p>Myers, L., Fleming, M., Lancman, M., Perrine, K., &amp; Lancman, M. (2013). Stress coping strategies in patients with psychogenic non-epileptic seizures and how they relate to trauma symptoms, alexithymia, anger and mood. <i>Seizure</i>, 22(8), 634-639. doi:10.1016/j.seizure.2013.04.018</p> <p><b>Objective:</b> To determine typical coping responses of patients with psychogenic non epileptic seizures and to determine whether the maladaptive approach to coping is associated with other/ underlying psychopathology</p>	<p>Purposive sampling at an Eastern US epilepsy program.</p> <p><b>Inclusion:</b> Consecutive enrollment of first 100 patients with the diagnosis PNES</p> <p><b>Exclusion:</b> IQ &lt;70, dual diagnosis, invalid data collection .</p> <p>n= 82; 10 males and 72 females.</p> <p>Sample demograp</p>	<p>Application of composite tool which assesses coping styles and the style</p> <p>Seven measures used in study: five psychological and two which identified intelligence and malingering for exclusion.</p> <p>Tool administered by trained neuropsychologists</p> <p>Results from application of tool sorted into one of three sub-types</p>	<p>Majority of sample demonstrated a predisposition toward emotion focused coping strategies.</p> <p>Those who employed a task orientation to coping reported less psychopathology.</p> <p>Emotional orientation to coping is correlated with avoidance and abuse.</p> <p>Nearly four out of five people in the sample diagnosed</p>	<p><b>Strengths:</b> Definition of trauma as a classification is well articulated.</p> <p>Validity measures are strong and resource location provided for additional information relating to measures from which the composite tool was</p>	<p>Distribution of gender in sample is representative of correlation of PNES with female gender which offers findings weight and generalizability.</p> <p>Exposure to traumatic stress (physical, sexual, other) has strong relationship with expression of PNES in 76% of sample.</p>

	<p>tics and characteristics were not presented .</p>	<p>ANOVA used to compare T scores and Chi squares to identify frequency and p value set at .05 to determine significance.</p>	<p>with PNES had been exposed to abuse: 58% physical; 47% sexual; 28% both.</p>	<p>designed.</p> <p><b>Limitations:</b> Exclusion 8% of subjects 2* to personality subtype despite confirmed PNES is not representative of population and investigations is selective not consecutive as an enrollment strategy</p> <p>No statement in relation to inter-rater reliability or measures employed to</p>	<p>Exposure to abuse and diagnosis of PNES predictive of tendency towards particular coping strategy; avoidance (p=0.005), emotion focused (p=0.001).</p> <p>Very strong correlation between maladaptive emotion-oriented coping strategy versus task-oriented and PNES (p= .0001) as well as avoidance (p=.001).</p> <p>Rating: Strong</p>
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				mitigate variation in scoring	
				Ethnicity was not discussed which does not reflect or control for typified coping responses of sub-groups.	

Citation and Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/and Limitations	Conclusion and Rating
Duncan, R., Graham, C. D., Oto, M., Russell, A., McKernan, L., & Copstick, S. (2014). Primary and secondary care attendance, anticonvulsant and antidepressant	Consecutive enrollment of patient diagnosed with PNES from specialized seizure clinic (n=260) Purposive sampling took place	260 patients diagnosed with PNES were followed for ten years following diagnosis with PNES. Exclusion and	At baseline, 32% of sample had attended primary care or hospital with c/o 'seizure' (p<0.001). Emergency care attendance reduced by 31% following	<b>Strengths:</b> Procedure through ethics was well articulated. Challenges traditionally held beliefs in relation to latency to diagnosis and seizure outcome. This	Patients employed at baseline were 6.5 times more likely to be employed at 5 and 10 year follow up (p<0.001). Data available suggests

<p>nt use and psychiatric contact 5-10 years after diagnosis in 188 patients with psychogenic non-epileptic seizures. <i>Journal Of Neurology, Neurosurgery &amp; Psychiatry</i>, 85(9), 954-958. doi:10.1136/jnnp-2013-306671</p> <p>Objective: (a) To determine the extent to which people who have PNES are exposed to antiepileptic and antidepressant agents as well as contact with HCPs over time. (b) To add depth to the literature surrounding long-term health outcomes for people with</p>	<p>over five year period (1999-2004). Study site: Large urban area in Southern Scotland</p> <p>Baseline data revealed sample had: 76% women, 11% epilepsy + PNES, 6% had identifiable learning disability. All participants had 'attended with seizures' prior to enrollment.</p>	<p>negative response rate (including death) eliminated 20 people from participation. Clinical data related to healthcare utilization at primary and secondary care entry points were obtained and paired with informant GP attached to patients at year 5 and year 10. Investigators pursued GPs following</p>	<p>diagnosis at five and ten years. Antiepileptic drug (AED) prescriptions decreased by 38%; Those prescribed AEDs at baseline were 2.9 times more likely to remain on AEDs at 5 and 10 years. Exposure to trauma/psychiatric co-morbidity (self-harm) holds very strong predictive value (<math>p \leq 0.001</math>) for psychiatric contact and exposure to psychiatric medication.</p>	<p>study reports this variable to have no predictive value and identifies need for further study. Study well adapted to an considerate of local context; model which maintains connection with GPs (91%) may serve as exemplar for other services which are also part of 'closed' entry local healthcare system. <b>Limitations:</b> presentation limited to 'attendance with seizures' may contribute to underestimation of population health problem as seizures are not always</p>	<p>people diagnosed with PNES are unlikely to secure/maintain employment. Patients with long duration of untreated PNES are likely to continue to experience PNES long term. Substantial minority of patients retain significant psychiatric comorbidity into long term follow up. Study supports screening of people for exposure to trauma upon entry to diagnostic unit and access to specialized</p>
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PNES. (c) whether there is a correlation between PNES and employment.		changes of address which helped to maintain sample participation.		correctly identified. Self-report identified by investigators as source of conflict when ability to cross-reference/confirm with objective data exists. Healthcare attendance does not account for alternative or illicit healthcare measure utilization. Differentiation between PNES and epileptic seizure was not offered which has deleterious effect on generalizability and specificity of results.	providers Rating: Moderate- requires some extrapolation to make results meaningful
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Citation and Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/and Limitations	Conclusion and Rating
<p>Pretorius, C., &amp; Sparrow, M. (2015). Life after being diagnosed with psychogenic non-epileptic seizures (PNES): a South African perspective. <i>Seizure</i>, 3032-41 10p. doi:10.1016/j.seizure.2015.05.008</p> <p>Objective: To explore the life experiences of people diagnosed with PNES in relation to resources and strategies available or used to manage PNES on the individual and group levels.</p>	<p>Purposive sampling at South African epilepsy unit via neurologist-researcher referral affiliation (n=10).</p> <p>Inclusion: video EEG confirmation of PNES,</p> <p>Exclusion: comorbid epilepsy</p> <p>Age range: 19-55; mean= 39.2y</p> <p>Majority of participants were female,</p>	<p>Exploratory research design.</p> <p>Semi-structured interviews thematically analyzed and transcribed.</p> <p>Interviews were sixty minutes in lengths to ensure saturation in data collection.</p> <p>Rigor was established via mitigation against reflexivity, made use of member validation and employed peer debriefing.</p>	<p>Themes: <i>individual challenges</i> include unexpected seizures, physical injuries, broken independence, disability, unemployment, disbelief</p> <p><i>systemic challenges</i> include poor rapport with HCPs, accessibility of health information relating to PNES, belief system not integrated into</p>	<p><b>Strengths:</b> Value of the study lies in articulation of veiled and unfamiliar subjective experience of people who have PNES, in particular the role of HCPs as .</p> <p>Organization of themes into micro/meso/macro/exosystems help reader to appreciate the interaction amongst systems and pervasive nature of seizures</p> <p><b>Limitations:</b> Small</p>	<p>Study completion heralds the dual role of healthcare providers as a facilitator and a barrier to improvement for patients who experience PNES</p> <p>Religious exposure/involvement has a significant influence on patient conceptualization of seizures and decision to engage in treatment.</p> <p>When clinicians</p>



	unemployed, unmarried and engaged in psychotherapy and/or medication	Data organized via Bronfenbrenner's ecological lens and organized into four interrelated strata.	care, HCPs dual roles as support and barrier. <i>Social support</i> the extent to which person is supported in interpersonal relationships, employment, academics, isolation from peer group,	sample significantly limits generalizability. Limiting inclusion only to those with diagnosed PNES introduces selective bias. The bias present may not afford understanding the impact of PNES on all who have been diagnosed with the condition.	are cognizant of the stigma, potential for impaired emotional processing, psychological distress and limited social and occupational opportunities available to people with PNES, care is sensitive to the unique needs of this population.  Rating: Value of study completion lies in the unmasking of the experience of people with PNES, how this population
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					manages stress and the role of healthcare providers in relation to individual and population outcomes; Strong
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Citation and Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/and Limitations	Conclusion and Rating
Rawat, V., Dhiman, V., Sinha, S., Vijay Sagar, K., Thippeswamy, H., Chaturvedi, S., . . . Satishchandra, P. (2015). Comorbidities and outcome of childhood psychogenic non-	Patients recruited from an Indian tertiary psychoneurology hospital (n=44) Mean duration of illness before diagnosis was $0.83 \pm 1.2$ years (range:1-6 years; median 1.5 years.	Retrospective observational study spanning seven years (2005-2012). Medical records reviewed for past medical history, seizures, psychiatric comorbidity, family history and exposure to pharmacologic or psychosocial treatment Outcome properties determined	Total of 1281 EEGs completed during study period (763 adult; 518 children). 11% of sample diagnosed with PNES based on video EEG result (n=139) 32 % of those with PNES were children	Strengths: informed consent obtained prior to video-EEG for participation in investigation. Results speak to deleterious individual effects associated with PNES	Study achieved objective of articulating outcomes associated with childhood PNES. Study demonstrated >10% of EEGs performed will reveal PNES as diagnosis.

<p>epileptic seizures--an observational study. <i>Seizure the Journal of the British Epilepsy Association</i>, 25, 95-98.</p> <p>Objective: To assess the prevalence of psychiatric diagnosis in children who have been diagnosed with PNES.</p>	<p>Patients seizures assessed in epilepsy monitoring unit--seizures characterized by video EEG</p> <p>Inclusion: Diagnosis of PNES from epilepsy monitoring unit, &lt;16 y.o.</p> <p>Exclusion: post ictal slowing on EEG and seizures with a neurological origin.</p>	<p>number of follow up visits, family history of psychiatric disorder or epilepsy, exposure to psychotropic or psychosocial treatment, level of functioning WRT social or academic involvement</p> <p>Data integrated into spreadsheet and descriptive analysis employed.</p> <p>Analyses performed by R software (version 3.0.2) which is statistical/computational software.</p>	<p>(n=44). 34/44 children with PNES had conversion disorder as underlying psychiatric source of seizures with remainder having ADHD as primary diagnosis. Majority of children who underwent individual therapy responded well evidenced by reduction in events. 29/44 children were unnecessarily exposed to pharmacological agents; 53% of these children were</p>	<p>which when left unchecked will intensify and expand over time.</p> <p>Limitations: Discussion which resolved diagnostic differences was not disclosed. Retrospective design with relatively small sample size.</p>	<p>Repeated observations required to afford generalization</p> <p>Results caution physicians prescribing AEDs in the absence of video EEG diagnostics.</p> <p>Rating Moderate</p>
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			prescribed >1 AED		
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Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/ Findings	Strengths/ and Limitations	Conclusion and Rating
Santos, N., Benute, G., Santiago, A., Marchiori, P., & Lucia, M. (2014). Psychogenic non-epileptic seizures and psychoanalytical treatment: Results. <i>Revista Da Associação Médica Brasileira Publication of the Associação Médica Brasileira</i> , 60(6), 577-584.  Objective: To report on the effects	Purposive sampling via hospital-based epilepsy program referral arm (n= 37)  All patients treated as refractory epilepsy prior to study and not accepting concurrent psychiatric treatment  Average age= 32 (range 22-43); Average duration of	Prospective longitudinal design.  Consecutive enrollment between 2004-2007.  Participants were engaged in a scripted interviews prior to engaging in psychoanalysis to collect baseline and demographic data as well as to present diagnosis  Participants engaged in psychoanalytical	Following psychoanalytical treatment, ~30% realized a cessation or “cure” of PNES seizures (n=11); 51% experienced a reduction of seizures (n=19).  Statistically significant relationships between PNES and: psychoanalytical treatment (p<0.01), gender (p<0.01) and religion (p<0.01).	Strengths: results articulate the internal struggle surrounding psychological origin vs. an organic cause as well as disclosing this to others/ loved ones. This underscores the influence of stigma and misconceptions surrounding PNES.  Emphasizes the importance	This study does add value to the appreciation of subjective values and beliefs of those with PNES but does not come without significant limitations.  Application of psychoanalysis has demonstrated good effect as it relates to decreasing or cessation of seizures.  Psychoanalysis may have greater application for subpopulation

of individualized psychoanalytic treatment for people with PNES as it relates to a selection of individual or experiential criteria (gender, duration of seizures, social/ professional / emotional losses	<p>seizures =8 (range 2-17); 60% single/separated; Religions: Buddhist (n=2), Catholic (n=13), Spiritist (n=8), Evangelical (n=7), undisclosed (n=7).</p> <p>PNES diagnosis confirmed via video-EEG monitoring during admission to epilepsy monitoring unit.</p> <p>11 patients (2 male and 9 females) were reported to be unaccepting of PNES diagnosis and refused to participate.</p>	<p>treatment with a total duration of 48 fifty minute sessions over a 12 month period</p> <p>Effectiveness of intervention was measured by reduction or cessation of convulsive seizures.</p> <p>The results encountered were presented in the form of means, medians, standard deviations, absolute and relative frequencies.</p> <p>2x2 tables, the Fisher exact test and the nonparametric Mann-Whitney</p>	Relationship between treatment and duration of seizures (p=0.06) was not statistically significant.	<p>of the time/context surrounding diagnosis as it relates to outcome and engagement in treatment.</p> <p>Limitations: transcription of interview took place post interview from memory and may not be akin or completely in accord with actual events/ discussion.</p> <p>Improvement or variation in participant experience or outcome cannot be solely attributed to</p>	<p>(high functioning neurotic) versus general application thus appropriate for tailored intervention.</p> <p>The role of religion as it relates to engagement and treatment is significant especially for particular cultures.</p> <p>Rating: moderate. Access to clinicians who are practiced at psychoanalysis is limited and individuals must be able to engage as well as demonstrate insight into symptoms/seizures for there to be value in the intervention.</p>
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	These patients were therefore excluded from the study.	test were used.  To compare results in more than two groups, nonparametric Kruskal-Wallis test was employed.  A significance level of 0.05 ( $\alpha = 5\%$ ) was adopted. As such, descriptive levels ( $p$ ) lower than this value were considered as significant ( $p < 0.05$ )		intervention.  High costs associated to intensive psychoanalytic therapy may be barrier to replication of results in most centers.  No indication how researchers maintained sample and had no attrition over the course of the year long intervention.	
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Citation and Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/and Limitations	Conclusion and Rating
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<p>Acton, Emily K., &amp; Tatum, William O. (2012). Inpatient psychiatric consultation for newly-diagnosed patients with psychogenic seizures. <i>Epilepsy &amp; Behavior</i>, <i>Epilepsy &amp; Behavior</i>. Study Objective: To evaluate the prevalence and utilization of inpatient psychiatric consultations (IPC) amongst a sample of patients newly diagnosed with PNES</p>	<p>Epilepsy centers identified by US National Association of Epilepsy Centers were included in the survey investigation (n=173). Study settings were both paediatric only and paediatric and adult centers</p> <p>In separate investigation, patients consecutively enrolled in single center evaluation (n=26). Study setting was EMU founded in a large urban city in America.</p>	<p>Study approved by institutional review board and passed ethical standards committee. Electronic survey sent to the 173 Level 3 and 4 Epilepsy Monitoring Units and requested yes/no response to "Does your epilepsy center routinely obtain a psychiatric consultation for PNES patients in the EMU?" Fisher's test used to calculate significance (p=0.05). Single site study involved the review of 26 consecutive</p>	<p>83% of paediatric centers responded confirming psychiatric consultation is routine practice for suspected PNES versus only 36% of adult and paediatric centers</p> <p>All 26 patients included in single site investigation had been prescribed AEDs prior to diagnosis of PNES. Mood and anxiety disorders most common psychiatric diagnoses in this sample. In single site investigation</p>	<p>Strengths: Results of survey can be generalized considering breadth and inclusiveness of sample. Limitations: The results from the single site investigation cannot be generalized due to the small sample size and largely undisclosed patient characteristics. Survey has the potential for self-selection bias. There is potential for over/under estimation of IPC utilization with is a methodological threat as it was not controlled for. Retrospective design and</p>	<p>Successful treatment of PNES is predicated upon correct diagnosis Exposure to AEDs can be detrimental to health especially when unnecessary/contraindicated</p> <p>Comments provided by EMUs on survey demonstrative of the divide between Neurology and Mental Health which may hinder the recovery of some patients. Homogenization of two investigations is not possible due to local variability and self-selective context Reducing IPCs during inpatient admission is a</p>
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		ly admitted non-selected elective hospital patients diagnosed with PNES by video EEG. McNemar's test used to calculate significance (p=0.05)	on there may not be immediate benefit to IPC Of the epilepsy centers who provided comments in addition to the yes/no answer, 10% stated there is minimal or no interest in engaging psychiatry during admissions to EMUs.	lack of randomization are limitations of the single site investigation.	positive cost containment strategy; Case by case evaluation recommended. . Rating: study completion adds value to body of knowledge in relation to IPC utilization by EMUs and exposes limitation and outcomes associated with exposure to IPC during admission; Moderate
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Citation and Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/and Limitations	Conclusion and Rating
Duncan, R., Graham, C., Oto, M., Russell, A., Mckernan,	Purposeful sampling with consecutive enrollment	Retrospective longitudinal exploratory design	¾ of participants were female, 11% had	Strengths: Ethical progression through to publication	Results confirm the role of underlying mental health



<p>L., &amp; Copstick, S. (2014). Primary and secondary care attendance, anticonvulsant and antidepressant use and psychiatric contact 5–10 years after diagnosis in 188 patients with psychogenic non-epileptic seizures. <i>Journal of Neurology, Neurosurgery &amp; Psychiatry</i>, 85(9), 954. Study objective: To elaborate the long-term outcomes associated with PNES and to explore healthcare</p>	<p>of patients from PNES clinic (n=260). Over the course of investigation 72 patients died or refused to participate which resulted in a slightly smaller sample at year 10 (n=188). Study setting was large urban city in United Kingdom Timeline: 5 years (1999-2004). Patients who were not enrolled at year ten were excluded from analysis.</p>	<p>Chart reviews paired with other patient data bases which populate with unique national patient identifier. Data also obtained from contact with GP to confirm/clarity healthcare contact. Base line data compared against several variables including seizure characteristics, treatment, social program utilization, social history indices and exposure to pharmacological agents. Statistical analysis completed by software:</p>	<p>concurrent epilepsy, 6.4% had learning disability. Patients diagnosed with PNES at baseline were likely to have been prescribed an AED, to have exhibited self-harm behaviours and to have been prescribed an antidepressant Mean onset of PNES was 30.7 years (+/- 13.3 years). Delay to diagnosis 6.7 years (+/- 7.7 years). Employment at baseline is predictive of employment at year 5</p>	<p>is well articulated. Adds to the fractured body of literature surrounding long-term outcomes associated with PNES as well as the detrimental sequelae which persists in the presence of PNES. Relatively large sample size. Limitations: self-selection bias may influence enrollment 'Seizure free' qualifier was not defined. Collecting data from GP does not gather data from the patient</p>	<p>condition in the expression of PNES. Significant exposure to pharmacological agents and exhibitions of self-injurious behaviours must not be overlooked The completion of the study is significant as it explores the long term outcomes associated with PNES in relation to quality of life indices and their relative stress or influence on divisions of the healthcare systems Limited presentations to hospitals with emergencies at five and ten year marks reflective of avoidant coping styles which are</p>
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utilization amongst this population.		SPSS V.19. Simultaneous regression models used to identify ability of independent variables to outcomes. Significance level set initially at 10% ( $p \leq 0.10$ ) and over three regressions independent variables significance established at 5% ( $p \leq 0.05$ ).	and 10. 14% of patients in study had attended hospitals with emergencies at 5 and 10 year review date +/- 6 months.	and therefore may not be representative of the experience of the person being surveilled. Referral bias may have been present in recruitment	prevalent amongst people diagnosed with PNES. Rating: Moderate-bias and misrepresentation likely to be present in data collected.
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Citation and Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/and Limitations	Conclusion and Rating
Elliott, J., & Charyton, C. (2014). Biopsychosocial predictors of	Consecutive enrollment of patients admitted to an epilepsy monitoring	Retrospective chart review of patients admitted to EMU	408/689 patients enrolled in study ended up with a	Strengths: All participants were diagnosed using video	Power of comprehensive results lies in the ability to draw associations

<p>psychogenic non-epileptic seizures. <i>Epilepsy Research, Epilepsy Research.</i> Study objective: To determine the predictive value of diagnosis as it relates to biopsychosocial variables.</p>	<p>unit (n=689). Study period: 6 years (2002-2007). Study setting: Epilepsy monitoring unit in a large urban city in an Eastern US state.</p>	<p>Patients identified by billing code which determined exposure to video EEG diagnostics. Data were obtained from review of electronic patient record, inpatient history, discharge summaries and physical exams completed by EMU. Biopsychosocial domain defined as age, gender, race/ethnicity, clinical factors: age of onset, duration (years) of seizures, history of head injury and diagnosis of intellectual disability Multivariate logistic</p>	<p>diagnosis of PNES following video EEG and EMU admission. Duration of time with seizures prior to video EEG was predictive of PNES diagnosis. Significant relationship with PNES diagnosis and head injury, asthma, GERD + use of gastric reflux medications. Univariate regression revealed female gender, psychological factors, and social factors exert significantl</p>	<p>EEG. Breadth of biopsychosocial factors analyzed for association with PNES is central to the articulation of the experience people with PNES. Relatively large sample size (n=689) offers a degree of authority as it relates to other studies in which PNES is the dependent variable. Predictive value resultant of quantification of prevalence in a sample offers clinicians insight into path toward expression of PNES.</p>	<p>between biopsychosocial factors/exposures and a diagnosis of PNES Results underscore the importance of considering a psychosocial domain when a diagnosis of PNES is suspected. Providers must be cognizant of the factors which precipitate and surround people who experience PNES. Perhaps being cognizant is not as consequential as acting to improve these same factors. Patients with concomitant epilepsy and PNES must also be in receipt of a holistic</p>
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		regressive analysis employed to determine which are the factors of significance as it relates to individual bisopsychosocial factors.	y more on expression of PNES as opposed to somatic indices.	Limitations: Control group was patients with confirmed psychosis. No characteristics/ information of control group disclosed beyond diagnosis.	approach to care planning and healthcare provision. Rating: Strong
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Citation and Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/ Findings	Strengths/ and Limitations	Conclusion and Rating
Asadi-Pooya, Ali A., Emami, Mehrdad, & Emami, Yasaman. (2014). Ictal injury in psychogenic non-epileptic seizures. <i>Seizure: European</i>	All patients with a diagnosis of PNES enrolled through outpatient epilepsy clinic (n=211)  Study period: 2002-2008 All diagnoses confirmed via clinical	Patients undergo 2 hour video EEG at outpatient clinic. Attempts to induce seizures are made and caregivers are consulted to confirm captured	67% of sample were female (n=141) and 33% male (n=70). 31% reported sustaining injuries since their seizures started.	Strengths: Confirms belief that when PNES expression is extreme or violent, injuries are likely and to be more severe. Research presents a model to predict	Physical injuries are common in people with PNES. The presence of injuries does not rule out PNES which is in contrast to the prevalent belief present in the medical community

<p><i>Journal of Epilepsy</i>, Seizure: European Journal of Epilepsy. Study objective: To describe the spectrum of ictal injuries sustained by people with PNES and to identify factors associated with ictal injuries in those patients.</p>	<p>evaluation and video EEG Study setting: Large academic teaching hospital in Iran which has both inpatient and outpatient healthcare arms.</p>	<p>events are representative of typical seizures Behaviour attribution of seizures made by semiology consensus. Patient information was de-identified Patient data summarized descriptively to characterize study population Binary logistic regression applied to variables identified as being significant during univariate analysis (<math>p &lt; 0.05</math>)</p>	<p>Most common injury are tongue biting, lacerations, hematomas and fractured bones Violent shaking, urinary incontinence and nocturnal seizures were strongly associated with PNES. Post ictal state and history of abuse were also associated with injuries.</p>	<p>which patients will report injuries secondary to PNES Limitations: A two hour EEG is unlikely to capture an event and does not afford a long enough period of observation to be considered representative of seizure frequency which could lead to injuries Injuries recorded are not representative of all injuries sustained by people with PNES. Physical injuries were not always objectively corroborated</p>	<p>The ability to predict injuries in subgroups (history of/exposure to abuse) of is of particular value to clinicians, patients, administrators and family members alike. The results need to be confirmed through repeated investigations to apply conclusions broadly. The quantity of people married in the sample may not be representative of cultural imperatives Rating: Moderate</p>
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Citation Study Objective	Sample/Gro ups (Size, Setting, Characteristi cs)	Design and Methodolog y	Key Results/ Findings	Strengths/ and Limitations	Conclusion and Rating
Novakova, Howlett, Baker, & Reuber. (2015). Emotion processing and psychogeni c non- epileptic seizures: A cross- sectional compariso n of patients and healthy controls. <i>Seizure</i> : European Journal of Epilepsy, 29, 4-10. Study objective: To explore the emotion processing styles of people diagnosed with PNES	Patients consecutivel y recruited to study from referrals to neurology program (n=55). All patients had diagnosis made by neurologist. Most patients had video EEG as a data point in their diagnosis. Demographi c and emotional processing data obtained from 224 healthy controls who were recruited from a variety of workplaces and	Prospective cross sectional study design. Patients screened for suicidality and suitability for psychothera py. Demographi c and clinical information supplied by patient and referring neurologist via questionnair e Data analyzed using SPSS(version 19). Mann- Whitney U tests used to determine scale of difference between emotional	50/55 patients returned a complete questionnai re and were included in the study Patients ranged from 17-74 years old. Healthy control groups aged 17-78 years old. No significant differences in age or gender when PNES and healthy controls are compared (p= >0.05). When compared broadly against healthy controls, the PNES	Strengths: Study demonstrates clear difference between the emotional processing styles and deficits of present in patients with PNES. The study design and recruitment achieved parity between PNES and control groups which has afforded considerable comparative power. The EPS tool is an amalgam of emotional and physical indices which offers insight via holistic representation of internal process and their influence on functioning	Study offers evidence supporting the application of the tool to identify coping styles and deficits in patients with or suspected to have PNES. Results may assist clinicians to focus their approach or treatment to target an aspect of emotion processing for improveme nt. This is a strong study design and adequate

as compared to healthy controls and to explore associations between emotion processing with other psychological measures and seizures through use of emotion processing scale	community sources. Controls gender and age matched with PNES group Study setting: Neurology program in academic teaching hospital in large urban area in United Kingdom	processing styles and abilities of the PNES group and the control group alike. Frequency of seizures was calculated by number of seizures monthly. Emotion processing scale administered which identifies emotional processing styles and deficits.	group demonstrated greater emotion processing deficits and emotional disturbance . The PNES group scored significantly poorer on all measures of emotional suppression , unprocessed emotion, avoidant coping style and impoverished emotional experience (p=0.001). When compared with the results of comparing the results of application of this same tool in PTSD and	or other body systems. Limitations: Cross-sectional design does not afford the ability to draw causative relationships between the dimensions assessed. Employing self-reports in data collection is inherently prone to bias and misrepresentation. Results and conclusions could be the result of a subgroup of the PNES population which was captured by the recruitment.	control is present in comparison between groups however the tool yields limited new information about patients with PNES following application of the tool
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			<p>pain patient populations , PNES group scored significantly higher in measures determinin g emotional deficits and suppressive coping styles</p>		
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Self-Directed Psychogenic Non-Epileptic Seizure

Nursing Learning Module

Consultation Report

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Memorial University

August 14, 2016

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## **Background**

Psychogenic non-epileptic seizures (PNES) are caused by underlying psychopathology which is expressed as a predisposed individual attempts to cope with

stress via flawed internal processes. PNES is a common condition for some individuals in a diagnostic epilepsy unit with 20-40% of all referrals to the unit receiving a diagnosis of PNES (Martin et al., 2003; Asadi-Pooya, & Sperling, 2015). Adapting this estimate to the local context, a discharge diagnosis of PNES will have been provided to about 144 of the 359 of patients admitted the diagnostic epilepsy unit at London Health Sciences Centre (London Health Sciences Centre, 2016). Given the established presence of non-epileptic patients in epilepsy units, it is imperative that the nursing care provided to all patients is holistic in nature and tailored to the needs of the individual. Hence, an epilepsy-centric model to patient care can leave important precipitants unaddressed and may also adversely affect the functioning of the individual.

The current practicum project has its roots in an observation made in clinical practice that patients with PNES may be underserved by diagnostic epilepsy units. Further to this end, it was suspected that nurses who were inexperienced working in diagnostic unit practice settings or those who are naïve to the needs to a patient with PNES could act as a barrier to treatment and recovery in these same patients. A cursory inquiry into the experience of people with PNES revealed healthcare for this population is often uncoordinated resulting in a pervasive gap in healthcare. Additionally, this early inquiry also exposed paucity in literature surrounding effective nursing in-patient care models for PNES. This knowledge prompted the identification of the creation of a self-directed nursing learning module for PNES as a goal for the current practicum project. In preparation for the creation of this learning module, an extensive review and critical appraisal of the literature was completed. This literature review not only identified how

teams and systems can influence health outcomes in this population and how nurses learn but also served to inform which professionals ought to be consulted in the development of a learning module. It would be through consultations that a need for such a learning module could be confirmed and to determine content for inclusion in the nursing learning module. Consultation with local and international experts working with people who have PNES as well as those with nurses experienced in the care of people with PNES admitted to diagnostic epilepsy units were viewed as being an essential means to the creation of a self-directed learning module. Feedback and the collective result of the consultations will serve to decide which information needs to be included in a PNES learning module to prepare nurses to work effectively with this population. Without these consultations, there could not be certainty that the learning module topics were the right ones and that these topics are packaged or delivered effectively.

### **Consultations**

The participants for the consultations were considered carefully. It was acknowledged early on that the groups of nurses working in the diagnostic epilepsy unit are a principle source of information. The experience of nurses not only working with patients who have PNES but also their experience working with inexperienced nurses or nurses naïve to PNES would be of particular value to confirming the need for a learning module. This expert nursing experience would be key to the cultivation of an understanding as to what knowledge or information nurses who are new to a diagnostic unit or are new to PNES as a diagnosis need to possess to be effective working in the unit

and with this patient population. Consultation of London Health Sciences Centre's eight diagnostic unit nurses did not go as planned. Unfortunately, the availability of the unit's nurses to attend a meeting in which the consultations were to occur did not permit for the consultation to be completed as a group. Instead, each of the unit's four nursing pairs were sought out during a scheduled tour which fortuitously provided additional unexpected opportunities. In addition to consulting all of the primary nursing staff, the opportunity was also presented to consult two casual nursing staff members, but perhaps most importantly, a nurse who had just joined the team from another hospital service prior to her first exposure in the unit. The consultation with the casual staff and the nurse new to the unit were of particular value as these nurses were able to reflect on their recent experience developing their abilities to work with PNES. The consultation with the *new* nurse provided an indication of what baseline understanding of PNES nurses who are inexperienced and naïve to diagnostic units possess prior to engaging in orientation and exposure to the unit and patients therein. In total, 10 nursing consultations were completed with an additional consultation completed with a burgeoning epilepsy nurse. The consultations completed with the nursing staff were comprised of meetings with nurses who possessed varied levels of nursing experience and exposure to nursing activities in a diagnostic unit. These consultations were completed in an anteroom near but not off of the unit so that privacy could be maintained. Participants were provided with the questions prepared in advance and no time limit was imposed to complete the consultations. However, these were completed in fifteen minutes in most cases.

Identification of experts for consultation was identified via a PNES-driven environmental scan. The environmental scan served to recognize and suggest individuals who could inform the project from a perspective different than nursing promoting a diverse, robust and holistic approach to learning module creation. Participants sought for consultation included professionals within the Epilepsy Program itself, local community organizations, as well as individuals from national and international diagnostic epilepsy units. The professions identified for consultation included membership from diverse disciplines such as physician neurologists, social work, neurodiagnostic administration, community education specialist, psychology and from a nurse practitioner. In total, six of eight consultations with identified experts were able to be completed. Unfortunately, two of the experts could not be reached for consultation due to scheduled absences however, these consultations will be completed in the remaining practicum semester and the results included in the final work. Recruitment of candidates was approached through in- person invitation, as well as electronic written and telephone communication to candidates outside of the hospital environment. While not all candidates who were initially targeted for consultation could be reached, in one case, consultation with an expert led to an opportunity to consult with a previously unidentified expert in PNES. Expanding the scope of the consultations slightly to accommodate this opportunity was endorsed by academic supervision and was recognized as being an important data source which should not be passed upon.

### **Methods, Data Collection and Data Management**

In most cases, the consultations were carried out as according to the intended plan. When necessary, obstructions to consultation and when reorganization of the plan was required these discussed with the academic supervisor which did include expansion of the consultation scope. These challenges included scheduled unavailability of two expert participants. It was unavailability however, which led to an opportunity for consultation with an expert psychologist. All of those invited for consultation were informed prior to their participation that the meeting was part of a quality improvement initiative and they could decide not to participate. No health care professional declined the consultation invitation. All consultations followed the prepared questions sequentially and the results were recorded (see Appendix A). Where necessary, the response was clarified for accuracy and validated against the respondent's intended message for authenticity. This was of particular importance when the consultation was completed by telephone as confirming nonverbal communication was not available. Consultation responses were subsequently entered into a password and firewall protected Excel spreadsheet which divorced the respondent from the response. It was noted during collation of responses when a database entry represented a response which had been provided multiple times.

### **Data Analysis**

Responses from nursing and the experts consulted were organized into themes separately and then as a collective using an iterative process. As a result of successive organization and reorganization, the responses were distilled into distinct themes. The

themes that emerged from this process will be used to identify content and structure a self-directed nursing PNES learning module. The themes which emerged from the data collection mirror in some ways, the themes present in the critical review of PNES literature. A theme which was recognized by all groups consulted was the need for an accessible overview of PNES. This information is regarded as being paramount to a nurse being able to effectively support the individual with PNES and to both understand the development of non-epileptic events but also to anticipate the needs of an individual with this condition. It was suggested by several respondents that an overview which included the origin of PNES, semiology and how diagnosis is made as well as delivered would be specifically assistive to preparing nurses to work with this inpatient population. A major subtheme which emerged were expert to novice 'clinical pearls'. The role of the healthcare provider (HCP) was also a central theme. It was identified that HCPs can act as a barrier and a facilitator of healthcare. When a particular element of care is not available or professional roles are poorly understood, psychology for example, the healthcare system can work against individuals with PNES imposing barriers such as, limitations to access. Importance was not only placed on the role of the nurse in relation to being omnipresent in the unit to help the individual cope during a non-epileptic event. It was also noted that if a nurse is unprepared, the nursing actions which compose the care for the individual can be misguided and in some cases, harmful or damaging to the individual. . A reassuring subtheme of advancing nursing competency in relation to assessment and management of PNES and supporting individuals with the condition will improve with exposure and experience in the diagnostic unit. A third theme which was



identified through analysis was the patient's life experience inside and outside of the diagnostic epilepsy unit. This theme encompasses experiences that people with PNES being stigmatized or marginalized by individuals and systems but also comments on the individual's to health care and as a recipient of health care as a life experience.

### **Implications for Results**

The consultations provided insight into a number of key issues relating directly relating to or surrounding the creation of a self-directed PNES learning module for nurses. The expert consultations wholly established the need for improved nursing care delivered to patients with PNES in diagnostic epilepsy units. It was also confirmed that this end could be attained through targeted education of nurses working with this patient population. expert and nursing consultations were particularly informative in relation to the reflections related to being new and the anticipation of what newly hired nurses who are new to the diagnostic unit are likely encounter in practice and therefore need to be prepared for. The nursing consultations revealed the nursing staff to be a remarkable source of experiential learning for new nurses but noteworthy is that not all nurses regarded themselves as possessing adequate knowledge relating to PNES to teach other/new nurses. The consultation with the new nurse confirmed that new nurses are very much unaware of the presence patients with PNES in the unit and as a result, are understandably underprepared to work with patients with PNES. Nearly all nursing respondents acknowledged that the Epilepsy Program could be doing more for patients with PNES while they remain patients of the diagnostic unit.

The themes identified will be used to structure the self-directed learning module to support nurses to effectively deliver nursing care to patients in the unit experiencing non-epileptic seizures. It was suggested during that the design a case study as a component of the learning module will facilitate operationalization the learning. The articulation of a hypothetical scenario where a dependent individual with PNES is no longer eligible for a disability pension given he is no longer suspected of epilepsy or an individual presenting to emergency care in suspected status epilepticus is revealed to have PNES following transfer from the Intensive Care Unit. As was emphasized by one of the expert respondents, health education by design is delivered to change behaviours and attitudes. It is in the spirit of this comment that the current practicum project is underpinned. The results of the consultations will be used to direct the architecture of the self-directed learning module. This module will be comprised of three main themes which will include, an overview of PNES, the life experience of people with PNES before, during and after admission to the diagnostic unit and the role of HCPs which will be nursing focused. The completed consultations also offers reflections from several careers working with the PNES population in the context of diagnostic epilepsy units which is adds considerable weight and impact to the end module. The information will be organized into an electronic presentation of learning module material with an accompanying learning manual. The electronic portion of the learning module will have to conform to a prescribed hospital template so that it may be adopted by the parent Organization of the current diagnostic unit. The learning module can then be electronically disseminated and completion tracked using the online learning platform

used at the hospital called *iLearn*. This will afford efficient means of assignment of the learning module to new nurses who are joining the unit to become part of their orientation in addition to the already available epilepsy orientation. This module could be the initial step in becoming a more comprehensive and patient centered Epilepsy Program and diagnostic unit.

### **Environmental Scan**

The environmental scan confirmed that formal hospital-based PNES programs, practiced healthcare providers and PNES-specific community support for people with PNES is fractured at best and non-existent in many cases. Significant variation was observed in relation to the degree to which diagnostic epilepsy programs outwardly acknowledged the presence of patients with PNES in their epilepsy units and fewer still who offered treatment to this population. The Environmental scan exposed professional, geographical and organizational inadequacies which act as barriers to recovery for people who have PNES.

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## Appendix A

### Expert Consultations

Question 1: Do you feel an opportunity exists to improve the quality of nursing care provided to patients diagnosed with PNES while admitted to a diagnostic epilepsy unit?	
Yes:	6
No:	0

Question 2: Do you believe a learning module relating to PNES could enhance the quality of nursing care provided to patients diagnosed with PNES?	
Yes:	6
No:	0

Question 3: What information do you feel nurses who are new to a diagnostic epilepsy unit or are inexperienced in nursing to know in order to meet the needs of people prior to and following PNES diagnosis?	
---	--

- PNES and epilepsy can co-exist as comorbidity
- Origin of condition
- Semiology++++
- HCPs need to make connections for these people to help them manage

- PNES community is fractured- people feel alone and isolated at diagnosis and beyond
- Be knowledgeable with respect to resources- Be prepared; proactive vs. reactive  
People will look to nursing for help and support
- Seizure/event experience is real; people are not malingering or faking
- Existence of co-morbid psychopathology can influence presentation and care
- Understand the role of each team member
- Tools (e.g. MMPI) and how they are used in diagnosis and determining care needs
- How to support people with Mental health conditions
- Incidence and prevalence - 20-40% of admits are coming for classification
- decoding language
- The length of time prior to diagnosis can be suggestive of how cemented seizures/illness is in their life
- Delivering diagnosis well promotes a better prognosis  
Be prepared; patients will ask nurses questions about PNES and don't defer to another team member if you don't have to
- Non epileptic seizures do not require pharmacy- be supportive
- condition can be stigmatizing and marginalizing
- Patients are suggestible and seizures can be provoked.++
- Validate experience as real event++++
- Make decision to take 'hand-off' approach but don't leave patient to feel alone

- Discharge planning needs to be robust- all team members (including nursing) have a role
- How diagnosis is made
- Meet people where they are at- tailor approach and nursing care to pt.
- Unit milieu can change depending on make-up of patient admission  
(Many patients with PNES in unit at one time can be frustrating)
- Seizures are part of identity and can support them financially
- diagnosis can be difficult to accept
- Stigma in HCPs and community + family
- Resources availability can differ dramatically depending on where home community is (North vs. urban vs. rural vs. international; cultural influences may be present)
- Understand the patient is not faking
- Patient may be with you for short time only, but nursing will prepare patient to engage in follow up/treatment post discharge

Question 4: What specifically would you want to be included in a self-directed nursing learning module for PNES?

- PNES definition++++
- Semiology+++

- Cautious use of language; "pseudo", "fake", "attention seeking"
- Fear and anxiety
- Reassurance to patients
- Stigma- reduce via education (HCPs + patients)
- Origin
- Risk factors++
- How diagnosis is made
- Treatment: CBT+++ and decreased antiepileptic drugs
- Resources for nurses and patients
- Articulation of the emotional needs of patients
- Seizure-like events are real phenomenon; don't invalidate them
- prevalence - 3/10 admissions have PNES- look for the clues
- PNES vs. epilepsy contrast
- It is a functional neurological disorder
- Know the role of all team members and how they come/work together
- Return to work
- Driving in this population
- Labeling events correctly
- Co-morbid- anxiety and migraine
- Stigma is very real
- How to support someone during and following dx.



- Active listening skills +interpersonal engagement
- \*\*Consider case scenario- comorbid epilepsy and PNEE
- Respond to all seizures and events with compassion and validation
- Know conversion disorders and somatoform (could be used to teach others)
- What typical post ictal phase for PNEE and epilepsy looks like
- Understand the patient is not faking+
- Much of the improvement in the condition will happen post d/c
- Few outpatient psychologists are interested in PNES and are effective

## Appendix B

### Nursing Consultations

Question 1: Do you feel as if you have a sound understanding of the origin of PNES and would you be comfortable teaching another nurse about PNES?	
Yes	7
No:	3

Question 2: What information about PNES would assist nurses who are new to the unit (NRT, new hire, 7 in-patients) to be effective when caring for their patients?
--

- General understanding which should include origin of events
- Semiology +++
- How PNES diagnosis is made
- Patient experience at time of diagnosis+++
- What is the role of nurse in relation to PNES
- PNES follow up care in community
- Interpersonal interactions- conflict, emotions
- rescue medication is not indicated In this population
- Validation of patient's experience
- The language used to describe the event
- Patients may be looking for organic cause to symptoms

May not receive diagnosis well++

- Both epilepsy and PNES can co-exist
- Presence of stigma and its existence within our team
- Strategies to engage PNES patients in nursing care
- Can be frustrating as a nurse to work with these [PNES] patients+++
- Talk and get to know your patient's story; helps to put the pieces together
- Secondary gains relating to remaining 'epileptic' can exist; think holistically
- PNES requires a different nursing response [vs. epilepsy]
- Be empathetic and don't promote seizure activity; Other patients are watching++
- Nurses need to manage co-morbid mental health conditions and emotions from patients
- Predisposing factors (divorce, trauma, gender)
- How patients are monitored in the diagnostic unit with technology
- Assessment and identification skills improve with experience +++
- We have to link these patients with the care they need
- All patients are to be approached with compassion and
- Review history and be familiar with risk factors++

Question 3: Can the Epilepsy Program to do more for our patients suspected of or diagnosed with PNES?	
Yes:	9

No:	1
-----	---

Question 4: Reflecting on your career in the unit, what have you learned about PNES that you wish you had known when you had started?

- Just how common it [PNES] is in an EMU++ (incidence and prevalence)
- Just how influential the psychopathological processes are
- Semiology/presentation of PNES vs. epileptic seizures are +++
- Prognosis
- People do not like to have their diagnosis changed from epilepsy to PNES++
- Ontario Disability Support Pension (ODSP)- PNES is not acknowledged by ODSP and without epilepsy dx= no \$
- PNES patients are often withdrawing from AEDs in unit.
- There are very few resources in the community
- Be empathetic with these patients++++
- The role of psychology and psychiatry
- tools: in the moment coping strategies
- PNES requires a different approach to nursing care vs. epilepsy
- Psychologists cost money in the community= barrier to access
- Can be frustrating working with this population

- Be aware of your own emotional expression
- nurses have a role in breaking stigma
- how technology [EEG] supports accurate diagnosis
- more experience one gets, the better their nursing care will become- watch and learn always++++
- Not everyone in EMU has epilepsy
- PNES patients require an emotionally sensitive nursing approach/response vs. hands on seizure first aid/ rescue medication
- Roles of the team members
- Just how serious this condition is
- These patients have significant needs during admission and after as well.
- The importance of family support when it is available is helpful to patient and staff
- Post ictal phase is very telling of whether event is PNES++

## Appendix C

### New Nurse Consultation

Question 1: Can you describe what psychogenic non-epileptic seizures (PNES) are?

- “No. I have no idea”.

Question 2: What do you think the origin or cause of PNES is?

- “I can only guess”
- Admitted she was naïve to the origin of non-epileptic events

Which healthcare professionals might be able to help patients with PNES

- “Since they are in the Epilepsy Unit, I would say the neurologist and the nurses”

Legend: ‘+’ = multiple identical responses received

## **Appendix D:**

### **Consultation Themes**

#### Theme 1

##### Overview of PNES

- Origin
- Incidence and prevalence
- Semiology
- How diagnosis is made and delivered
- Real phenomenon; people are not faking
- Contrast between epilepsy and PNES  
PNES can be comorbid with epilepsy
- Pharmacy  
Non epileptic seizures do not require pharmacy- be supportive
- The length of time from onset to diagnosis can be indicative of how cemented the pathology is

- Unit milieu can change depending on make-up of patient admission  
(Many patients with PNES in unit at one time can be frustrating)
- Resources availability can differ dramatically depending on where home
- community is (North vs. urban vs. rural vs. international; cultural influences may be present)
- Patient may be with you for short time only but nursing will prepare patient
- to engage in follow up/treatment post discharge
- PNES definition++++
- Semiology+++
- Cautious use of language; "pseudo", "fake", "attention seeking"
- Fear and anxiety
- Reassurance to patients
- Stigma- reduce via education (HCPs + patients)
- Origin
- Risk factors++
- How diagnosis is made
- Treatment: CBT+++ and decreased antiepileptic drugs
- Resources for nurses and patients
- Articulation of the emotional needs of patients
- Seizure-like events are real phenomenon; don't invalidate them
- prevalence - 3/10 admissions have PNES- look for the clues
- PNES vs. epilepsy contrast

- It is a functional neurological disorder
- Know the role of all team members and how they come/work together
- Return to work
- Driving in this population
- Labeling events correctly
- Comorbid- anxiety and migraine
- Stigma is very real
- How to support someone during and following dx.
- Active listening skills +interpersonal engagement
- \*\*Consider case scenario- comorbid epilepsy and PNEE
- Respond to all seizures and events with compassion and validation
- Know conversion disorders and somatoform (could be used to teach others)
- What typical post ictal phase for PNEE and epilepsy looks like
- Understand the patient is not faking+
- Much of the improvement in the condition will happen post d/c
- Few outpatient psychologists are interested in PNES and are effective
- Interpersonal interactions- conflict, emotions
- From expert to novice- Be aware of:
  - Just how common it [PNES]is in an EMU++  
incidence and prevalence
  - Just how influential the psychopathological processes are
  - Semiology/presentation of PNES vs. epileptic seizures are +++



- Prognosis
- People do not like to have their diagnosis changed from epilepsy to PNES++
- ODSP- PNES is not acknowledged by ODSP and without epilepsy dx= no \$
- PNES patients are often withdrawing from AEDs in unit.
- There are very few resources in the community
- Be empathetic with these patients++++
- The role of psychology and psychiatry
- tools: in the moment coping strategies
- PNES requires a different approach to nursing care vs. epilepsy
- Psychologists cost money in the community= barrier to access
- Can be frustrating working with this population
- Be aware of your own emotional expression
- nurses have a role in breaking stigma
- how technology [EEG] supports accurate diagnosis
- more experience one gets, the better their nursing care will become- watch and learn always++++
- Not everyone in EMU has epilepsy
- PNES patients require an emotionally sensitive nursing approach/response vs. hands on seizure first aid/ rescue medication
- Roles of the team members
- Just how serious this condition is
- These patients have significant needs during admission and after as well.

- The importance of family support when it is available is helpful to patient and staff
- Post ictal phase is very telling of whether event is PNES++
- General understanding which should include origin of events
- Semiology +++
- How PNES diagnosis is made
- Patient experience at time of diagnosis+++
- What is the role of nurse in relation to PNES
- PNES follow up care in community
- Interpersonal interactions- conflict, emotions
- rescue medication is not indicated In this population
- Validation of patient's experience
- The language used to describe the event
- Patients may be looking for organic cause to symptoms
- May not receive diagnosis well++
- Both epilepsy and PNES can co-exist
- Presence of stigma and its existence within our team
- Strategies to engage PNES patients in nursing care
- Can be frustrating as a nurse to work with these [PNES] patients+++
- Talk and get to know your patient's story; helps to put the pieces together
- Secondary gains relating to remaining 'epileptic' can exist; think holistically
- PNES requires a different nursing response [vs. epilepsy]

- Be empathetic and don't promote seizure activity; Other patients are watching++
- Nurses need to manage comorbid mental health conditions and emotions from patients
- Predisposing factors (divorce, trauma, gender)
- How patients are monitored in the EMU with technology
- Assessment and identification skills improve with experience +++
- We have to link these patients with the care they need
- All patients are to be approached with compassion and respect
- Review history and be familiar with risk factors++

## Theme 2

### Individual Experience as Member of Public and as Patient

- Community support is fractured  
Inequities exist in location/region making access to service unattainable even for motivated individuals
- Length of time between onset of PNES and diagnosis can be suggestive of how non-epileptic events, as an element of influence, have disturbed general functioning
- Consultation participant identified a scenario to be used as case study:  
56 year old recently divorced female presents to her family physician in her small town reporting having had two "seizures" this past Sunday morning. Suspecting

epilepsy, the physician orders a titrating dose of an antiepileptic medication, advises her that her license is suspended and informs her of a referral having been made to a diagnostic epilepsy unit for classification. Three days after having met with her physician, she is found seizing by a neighbour and rushed to emergency care via ambulance in apparent status epilepticus. Medical intervention suggests emergent intervention with benzodiazepines and intubation due to anesthetic-induced respiratory insufficiency. Intubation damaged lung tissue and patient was admitted to ICU. Stat EEG revealed patient was not in status epilepticus. Once recovered, admission to diagnostic epilepsy unit confirmed diagnosis of PNES. Patient was discharged to the care of her family physician.

Noteworthy: Antiepileptic medications are not indicated in this population.

Without video-EEG, non-epileptic events can easily be confused for status epilepticus in emergency situations which will have algorithmic emergency management sequelae. Improper management of unclassified seizure activity can result in unfortunate outcomes for patients with non-epileptic events. Also unfortunate is that there is often limited or nil access to appropriate treatment which can impose a significant barrier to recovery.

- Ontario Disability Support Pension does not recognize PNES as a supportable disability. Significant value may be assigned to remaining eligible for support as an epileptic; money is not available if not diagnosed with epilepsy.
- Seizure/event experience is real. People are not malingering or faking
- Condition can be stigmatizing and marginalizing

- Patients are suggestible and seizures can be provoked.++
- Seizures are part of identity and can support them financially
- diagnosis can be difficult to accept
- Stigma in HCPs and community + family
- Patient experience at time of diagnosis+++
- Patients may be looking for organic cause to symptoms
- May not receive diagnosis well++
- Both epilepsy and PNES can co-exist
- Presence of stigma and its existence within our team
- Return to work
- Driving in this population
- Stigma is very real
- Much of the improvement in the condition will happen post d/c
- Few outpatient psychologists are interested in PNES and are effective

### Theme 3

#### Roles of Health Care Providers

- Understand the role of all health care providers on the team

Psychology + tools

EEG

Nursing

Social work

Community Support

Neurologist

- How to support people with PNES  
mental health  
interpersonal dynamics  
validation
- HCPs need to make connections for these people to help them manage
- Health care for people with PNES can be fractured and inaccessible in many communities
- Be knowledgeable in relation to resources. Be prepared. Be proactive and not reactive.

People will look to nursing for help and support

- Decoding the language used to describe events for both patients and new nurses
- The length of time prior to diagnosis can be suggestive of how cemented seizures/illness is in their life
- Delivering diagnosis well promotes a better prognosis
- Be prepared; patients will ask nurses questions about PNES and don't defer to another team member if you don't have to
- Validate experience as real event++++
- Make decision to take 'hand-off' approach but don't leave patient to feel alone

- Discharge planning needs to be robust- all team members (including nursing) have a role
- Meet people where they are at- tailor approach and nursing care to pt.
- Understand the patient is not faking
- We have to link these patients with the care they need
- Active listening skills +interpersonal engagement
- Respond to all seizures and events with compassion and validation
- Know conversion disorders and somatoform (could be used to teach others)
- What typical post ictal phase for PNEE and epilepsy looks like
- Understand the patient is not faking+

Legend: + = multiple identical responses received

## Appendix E

### Health Research Ethics Authority Screening Tool

	Question	Yes	No
1.	Is the project funded by, or being submitted to, a research funding agency for a research grant or award that requires research ethics review	<input type="checkbox"/>	<input type="checkbox"/> <input checked="" type="checkbox"/>
2.	Are there any local policies which require this project to undergo review by a Research Ethics Board?	<input type="checkbox"/>	<input type="checkbox"/> <input checked="" type="checkbox"/>
	<b>IF YES</b> to either of the above, the project should be submitted to a Research	<input type="checkbox"/>	<input type="checkbox"/>

	Ethics Board.  <b>IF NO</b> to both questions, continue to complete the checklist.		
3.	Is the primary purpose of the project to contribute to the growing body of knowledge regarding health and/or health systems that are generally accessible through academic literature?	<input type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/>
4.	Is the project designed to answer a specific research question or to test an explicit hypothesis?	<input type="checkbox"/>	<input type="checkbox"/>
5.	Does the project involve a comparison of multiple sites, control sites, and/or control groups?	<input type="checkbox"/>	<input type="checkbox"/> <input checked="" type="checkbox"/>
6.	Is the project design and methodology adequate to support generalizations that go beyond the particular population the sample is being drawn from?	<input type="checkbox"/>	<input type="checkbox"/> <input checked="" type="checkbox"/>
7.	Does the project impose any additional burdens on participants beyond what would be expected through a typically expected course of care or role expectations?	<input type="checkbox"/>	<input type="checkbox"/> <input checked="" type="checkbox"/>
<b>LINE A: SUBTOTAL Questions 3 through 7 = (Count the # of Yes responses)</b>		1	
8.	Are many of the participants in the project also likely to be among those who might potentially benefit from the result of the project as it proceeds?	<input type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/>
9.	Is the project intended to define a best practice within your organization or practice?	<input type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/>



10.	Would the project still be done at your site, even if there were no opportunity to publish the results or if the results might not be applicable anywhere else?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
11.	Does the statement of purpose of the project refer explicitly to the features of a particular program, Organization, or region, rather than using more general terminology such as rural vs. urban populations?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
12.	Is the current project part of a continuous process of gathering or monitoring data within an organization?	x	
<b>LINE B: SUBTOTAL Questions 8 through 12 = (Count the # of Yes responses)</b>		<b>5</b>	
<b>SUMMARY</b>  <b>See Interpretation Below</b>			

**Interpretation:**

- If the sum of Line A is greater than Line B, the most probable purpose is **research**. The project should be submitted to an REB.
- If the sum of Line B is greater than Line A, the most probable purpose is **quality/evaluation**. Proceed with locally relevant process for ethics review (may not necessarily involve an REB).
- If the sums are equal, seek a second opinion to further explore whether the project should be classified as Research or as Quality and Evaluation.

**These guidelines are used at Memorial University of Newfoundland and were adapted from ALBERTA RESEARCH ETHICS COMMUNITY CONSENSUS INITIATIVE (ARECCI). Further information can be found at: <http://www.hrea.ca/Ethics-Review-Required.aspx>.**



# **Psychogenic Non-Epileptic Seizure (PNES): A Self-Directed Learning Module for Nurses**

**Daniel Robinson  
November 10, 2016**

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## **Welcome to the London Health Sciences Centre Psychogenic Non-Epileptic Seizure (PNES) Self-Directed Learning Module for Nurses!**

### **Why is a Learning Module of Interest to an Epilepsy Unit Nurse?**

The College of Nurses of Ontario (CNO), the governing body of both Registered Nurses and Registered Practical Nurses provides an organizing structure which guides the practice of all nurses. The CNO *Professional Standards* (2002) is a framework which articulates practice and professional expectations which apply to all nurses in all practice environments. Central to the practice standards is continuing competence which underscores every nurse's obligation to engage in learning to develop and increase competence. As a result of continuing learning, you will promote the development of quality in nursing skill, knowledge and judgment (College of Nurses of Ontario).

### **Instructions for the Learning Module**

You are encouraged to progress through the module at your own pace. This module may be used in the orientation to the diagnostic epilepsy unit by student nurses or nurses whom are inexperienced providing nursing care in epilepsy units. This resource may also be used by experienced nurses who would like a review at any time. For the purposes of this learning module, the term *nurse* will apply to both registered nurses and registered practical nurses.

### **Purpose of Learning Module**

The purpose of this learning module is to increase the PNES-related knowledge of nurses working in the diagnostic epilepsy unit at London Health Sciences Centre, London, Ontario. It has become apparent from direct observation that nurses orienting to the diagnostic unit are familiar with epilepsy. However, there are some nurses who are unaware of the presence of patients with PNES probably the result of being inexperienced in their care. The aim of this module is to provide both novice and inexperienced nurses with information in relation to PNES prior to engaging in providing nursing care to individuals in their patient assignment. .

**Section 1:**  
**An**  
**Introduction**  
**to PNES**

## PNES Overview

### Quick Facts

- PNES is the medical condition most often mistaken for epilepsy for at least 30% of patients making misdiagnosis likely for many (Sahaya, Dholakia & Sahota, 2011; Dworetzky, Weisholtz, Perez, & Baslet, 2015).
- As many as 87% of people eventually diagnosed with PNES have been prescribed an antiepileptic pharmacological agent (De Paola et al., 2016; Kerr et al., 2016).
- Incidence of PNES is estimated to be between about 3 and 5 new cases per 100,000 people per year. The prevalence of PNES in the general population is unknown but is estimated to be between 2-33 per 100,000 people (Asadi-Pooya & Sperling, 2015)
- 20-50% of patient referrals to diagnostic epilepsy units will have an exit diagnosis of PNES (Salinsky, Storzbach, Goy, Kellogg, & Boudreau, 2016).
- Diagnostic epilepsy units which employ video-EEG monitoring have the tools to provide an accurate diagnosis of PNES in nearly all cases (Chen-Block et al., 2016).
- PNES and epilepsy can be co-morbid in an individual (Magaudda et al., 2011).
- With engagement in treatment and care, the prognosis is favourable for PNES to completely resolve (Wiseman, Mousa, Howlett, & Reuber, 2016).
- People with PNES are not ‘faking’ or feigning PNES and as such, do not have volitional control over where or when they may have an event (Sahaya, Dholakia, Lardizabal, & Sahota, 2012).
- PNES is more likely to present in females and onset is likely in adolescence or adulthood, but can occur in children as well as the elderly (Asadi-Pooya, 2016).





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## Section 1 PNES Overview

### **Learning objectives**

Upon completion of section 1, the nurse will be able to:

- Describe PNES
- Describe the origin of PNES
- Identify risk factors associated with PNES
- Discuss the prevalence and incidence of PNES
- Describe PNES semiology
- Understand PNES diagnosis in relation to the role of the diagnostic epilepsy unit
- Discuss treatment pathways for PNES
- Increase current knowledge of nursing interventions for PNES





## **I**ntroduction to PNES

In this section, you will be provided with an overview of Psychogenic Non-Epileptic Seizures (PNES). This overview will help you to understand what PNES are, how they are produced and what contributes to psychogenic seizure production in patients. Additionally, you will learn how common the condition is and that it is very likely that you will be providing nursing care to a patient experiencing PNES during your next shift in the diagnostic epilepsy unit. In Appendix A, you will find a quiz to challenge your comprehension. Appendix B contains a video link of empathy that will support your work with PNES as a nurse in the diagnostic epilepsy unit.

## **W**hat are Psychogenic Non-Epileptic Seizures?

Epileptic seizures can be defined as a sudden involuntary event in which a person's brain discharges uncoordinated electrical activity producing a loss of muscle control in all or some parts of the body with an accompanying loss of awareness (Marcovich, 2010). In contrast to epileptic seizures and despite the similar presentation, PNES are not the sequelae of uncoordinated neuronal activity rather are the involuntary manifestation of an ineffective coping response to underlying psychological distress. Impaired emotional processing is associated with psychological distress. This can result in damaging interpretations and misattribution of symptoms which emerge in response to or precipitate PNES (Novakova, Howlett, Baker, & Reuber, 2015). PNES can have a significant influence on general functioning, health, and identity in relation to self and others, as well as healthcare utilization. It is very important to note that PNES can be co-morbid with epilepsy. People who have PNES also experience alexithymia which is an inability to identify and describe emotions in one's self. Unfortunately, many people with PNES have been misdiagnosed and may have been prescribed antiepileptic drugs which can be harmful. It can also significantly delay correct diagnosis and entry to treatment.

## **O**rigin of Psychogenic Non-Epileptic Seizures

Recent evidence suggests that PNES have neurobiological and neuropsychiatric origins (Assadi-Pooya & Ali, 2015; Assadi-Pooya & Sperling, 2015; Barzegaran, Carmeli, Rossetti, Frackowiak & Knyazeva, 2016). This means that the arrangement of the neuronal network in the brain of the affected individual has a role in the propagation of the seizure. When in the

presence of psychological distress, this network is predisposed to produce a maladaptive coping response causing losses of awareness and muscle control expressed as a seizure. Here, a psychological stressor can produce a



debilitating physiological reaction in an otherwise healthy person. To understand this complex event, think of how an emotion, thought or situation can lead to anxiety which in turn can produce physical effects such as palpitations or diaphoresis. The degree to which someone will be affected by anxiety in this example can be influenced by how the person's brain is 'hardwired' to respond to anxiety. It is noteworthy to remember that PNES are involuntary paroxysmal events.

## **R**isk Factors

PNES occurs in a heterogeneous population and as a result, there is no single factor which will lead to the onset of PNES. Given that PNES is associated a psychological insult and a bias toward an ineffective coping response, there are factors or situations which promote PNES in a predisposed individual.

Factors identified as having an association with the development of PNES:

- ✓ sexual abuse
- ✓ physical abuse (including neglect),
- ✓ traumatic brain injury,
- ✓ medical illness,
- ✓ losses such as employment or relationship
- ✓ female gender

(Assadi-Pooya & Sperling, 2015).



It is important to be cognizant that while completing or reviewing an epilepsy unit admission nursing history, some patients may be uncomfortable disclosing a history of abuse. As a result, a profound influence on the patient's functioning may not be reported to the nurse or be known to the referring physician.



## **P**revalence and Incidence

Prevalence and incidence are terms used to describe diseases within a population and are often associated with epidemiology or the study of factors relating to disease and health of groups of people. Incidence refers to the rate at which new cases (or newly diagnosed) are identified in a given time period whereas prevalence refers to the total number of alive cases within a population at a given time. (Beyersmann, Gastmeier, & Schumacher, 2014) Prevalence is often reported as a fraction of the total population with the diagnosis or disease. While Canadian statistics are unavailable, the incidence of PNES in the United States is estimated to be between about three to five new cases per 100,000 people per year (Smith, 2014; Assadi-Pooya & Sperling, 2015). The prevalence of PNES in the general population is unknown but, is estimated to be between 2-33 per 100,000 people (Benbadis & Allen-Houser, 2000; Smith, 2014; Assadi-Pooya and Sperling. It is accepted that PNES will be the discharge diagnosis for 20-50 % of patient admissions to diagnostic epilepsy units (Smith, 2014; Salinsky, Storzbach, Goy, Kellogg, & Boudreau, 2016). For nurses working in diagnostic epilepsy units, it is very likely that your patient assignment will include individuals who have PNES. And it is essential that you become familiar with PNES to provide patient and family-centered nursing care.

## **S**emiology

Semiology is the study of signs and their meaning. When applied to seizures, semiology refers to how the seizure is expressed by the individual or the actions/behaviours that can be witnessed when a person has a seizure. Close scrutiny to seizure expression has identified a series of movements or semiologic features which can be used to help contrast an epileptic seizure from PNES. These ictal features include closed eyes, side to side head movements, out of phase limb movements, arching of the trunk, intense rotation in bed and an interruption/fluctuation of seizure course evolution (Nežádal et al., 2011; Goldstein and Melleurs, 2012; De Paola et al., 2016). Correct identification of these semiologic features can assist neurologists with the diagnosis of patients. Unless present at the time of a seizure, the ability for the neurologist or epileptologist to assess seizure semiology as part of the diagnosis lies in the video recording of the patient during the time of a seizure. It is therefore very important to take note of your position in relation to that of the camera when you respond to a suspected or actively seizing patient. Nurses working in a diagnostic epilepsy unit are cautioned in relation to the interpretation of seizure semiology as the sole assessment in the determination of appropriate nursing care or nursing intervention. Semiology is interpretational and as a result, inexact. Misinterpretation could lead to serious medical consequences for patients



such as, status epilepticus. It is the neurologist who will make use of seizure semiology for diagnosis, while it can assist nurses to understand how a diagnosis is made for the patients.

## **D**iagnosis of PNES

An electroencephalogram (EEG) is a diagnostic intervention which uses electrodes attached to the individual's head to detect brainwave patterns or abnormalities or to rule out other conditions including epilepsy and PNES. EEGs are used in the diagnosis of epilepsy, but can produce misleading results or may not adequately identify an underlying cause. Conversely, EEGs may identify abnormal brain activity. However, if this abnormal activity does not correlate with functional impairment, it will not be of use to establishing diagnosis. Misleading EEG results may be the result of the person taking antiepileptic drugs or if epileptic activity is not captured by the diagnostic equipment for example. EEGs therefore cannot be relied upon alone to confirm PNES or to rule out epilepsy. Semiology of the seizure is a very important contributor to correct

diagnosis. Expert Epileptologists can sometimes attribute seizures to PNES based on a description of the seizure appearance.



Recall, there are clues in seizure semiology which can help to attribute a seizure to PNES. Continuous video-EEG is considered to be the gold standard for ruling out epilepsy from a PNES diagnosis (Dickinson & Looper, 2012; Perez & LaFrance, 2016).

Video EEG is recommended by the International League Against Epilepsy to differentiate epilepsy from PNES and can provide a definitive diagnosis in nearly all cases (Gedzelman & LaRoche, 2014; Hupalo, Smigielski & Jaskolski, 2016). Video-EEG diagnostic capabilities is the main reason why patients are referred to the epilepsy unit for classification. As a result, these are the patients that you will provide nursing care. While not completely understood, when diagnosis is delivered to the patient, it has been noted that upwards of 30% of patients will experience symptom resolution without any further intervention (Gedzelman & LaRoche, 2104). The EEG when paired with a video capture of the seizure can provide a neurologist or epileptologist with the elements required to issue an accurate diagnosis of PNES.



## **T**reatment

With as many as three quarters of patients eventually diagnosed with PNES will have been prescribed antiepileptic medications, it is therefore likely that treatment will begin with the tapering and discontinuation of medication(s) during their hospital admission (Dickinson & Looper, 2012). PNES is a condition which will require specialized professional support from a psychotherapist or a psychiatrist, and in some cases both, for the management and resolution of symptoms. Treatment for many individuals with PNES will often involve psychoeducation, psychotherapy and the initiation of psychiatric medications or a combination of these interventions (Chen & LaFrance, 2016; Wiseman, Mousa, Howlett, & Reuber, 2016).



Cognitive behavioural therapy (CBT) is a structured time-limited problem-focused form of psychotherapy which assists people to build skills and have strategies to understand the link between what is thought and what is felt by them. CBT has demonstrated efficacy as a stand-alone treatment, as well as a part of a multimodal approach care in the treatment of PNES (LaFrance et al., 2014; Haykal & Smith, 2015; Chen & LaFrance, 2016). A structured treatment modality such as, psychotherapeutics or engagement with a treating psychiatrist is not currently available to inpatients of the epilepsy diagnostic unit at London Health Sciences Centre. These services require referral to ambulatory care or community providers. While the patient diagnosed with PNES remains admitted to the diagnostic epilepsy unit, treatment may move forward with a pharmacological agent to address underlying contributors or co-morbidities to PNES such as, anxiety or depression.

## **N**ursing Interventions

Patient-centered nursing care is required as part of the interdisciplinary approach to the management of PNES in the diagnostic epilepsy unit. Nursing care should be holistic in nature, however, it should also prioritize management of medical needs, safety, promotion of self-esteem and health teaching. The management of medical needs should be considered part of routine nursing care, but some aspects of nursing care will be tailored to the needs of the patient with PNES. Given that PNES are not the result of epileptic brain activity, antiepileptic medications are not indicated in the medical management. As a result, patients may be down-tapering or discontinuing antiepileptic medications which they have been prescribed prior to admission. Nursing care needs to be cognizant of the medical implications for patients when discontinuing antiepileptic medications and recognize that the patient may be reluctant to discontinue a longstanding or familiar pharmacological agent. Connection with the pharmacist from the Clinical Neurosciences Program may be of benefit



should you have questions after reviewing the pharmacological profile of the particular agent being discontinued for the patient(s).



Empathy refers to interpersonal emotional knowledge and the ability to interpret the emotions of your patient as well as the precipitants to these emotions and the related consequences (Morrison et al., 2016)

Empathy is crucial to being present with any patient and will be central to the helping relationship with this person. Understanding empathy promotes agreement in relation to what it means to be a patient with PNES in a diagnostic epilepsy unit. Recall these individuals are not feigning or 'faking' their seizures. However, they may have been led to believe that they have been. Or consider what it may mean to your nursing care approach if you were to understand the 'lived experience of the patient' who have had seizures prior to admission to the unit or have learned during this admission, your seizures are not neurological, rather of a psychiatric origin. An empathetic approach to health care has been identified as being a primary contributor to recovery in patients (Lessar & Paleo, 2016). Nurses in diagnostic epilepsy units can help to engage patients in recovery through the therapeutic use of empathy which may prime the patient with PNES for the next step in their health care journey.

The instance surrounding the provision of a PNES diagnosis to patients can be considered to be a sensitive period because it relates to an individual's motivation and ability to cope following the admission to the diagnostic epilepsy unit (Karterud, Knizek, & Nakken, 2011). Patients may not receive the diagnosis of PNES favourably for a variety of reasons. Amongst these are factors which may predispose your patient to have a challenging time when receiving a PNES diagnosis. PNES may predispose your patient to impaired emotional processing resulting in unregulated emotional expression, avoidance or an impoverished emotional experience (Novakova, Howlett, Baker, & Reuber, 2015). The way that your patient processes emotional information may have an influence on how they will cope with their PNES. A characteristic avoidant coping style of people with PNES is associated with alexithymia as defense mechanism (Bilotta, Giacomantonio, Leone, Mancini, & Coriale, 2016). A predisposition of emotional processing impairment and an inability to identify and articulate how your patient is feeling may make the instance surrounding diagnosis a challenge to engagement in nursing care. In practice, emotional processing impairment may present in your patient as disengagement, indifference, hostility or disagreement. Knowing that your patient does not choose to have PNES is analogous to consider that your patient does not necessarily have control over how they will react to stress such as, receiving a PNES diagnosis. Furthermore, your patient may not yet have the skills to manage in the moment. The knowledge about PNES and a therapeutic use of empathy will help you to



remember that the provision of nursing care will require you to look beyond a deficit to find strength and believe in their ability to manage this condition.

## **Appendix A**

### **Empathy Video Link**

The empathy video link provided is a resource which has been created for the articulation of empathy in counselling individuals. While this resource has not necessarily been made with diagnostic epilepsy units in mind, the video does convey the tenants of empathy and helps to operationalize empathy through case examples. The video does implore nurses to respond to patients with a therapeutic empathetic approach to engagement in nursing care. The content of the video can be applied to all patients in the diagnostic epilepsy unit.

Empathy video link:

<https://stor.mun.ca/?r=36265&k=69bcb682e3>

## Appendix B

### Nursing Seizure Management Guidelines

Nurses can transfer into the diagnostic epilepsy unit from other hospital areas or programs and may not be familiar with epilepsy or PNES. This seizure management resource will complement the information you will receive during your orientation to the unit. The seizure management resource is presented to provide a framework to which you can tailor nursing care for your patient with PNES. The South Carolina Department of Disabilities and Special Needs provided permission to use their seizure management and response guidelines as a foundational resource for nurses working through this module. The nursing management plan is included as an introduction to the management of seizures during the latent and active stages of a nursing seizure response. Although it is an older resource, the content remains valid. You will note that the document has been created for the management of epileptic not psychogenic seizures. The nursing response to all seizures should always be patient-centered, focus on safety and the patient's experience using an empathetic approach to nursing care. The inclusion of this resource is meant to help nurses become familiar with basic epileptic seizure management if they have not managed a seizure in the inpatient diagnostic unit before.



Remember not to block the view of the camera when you are responding to seizures!

### Nursing Seizure Management Guidelines

<http://ddsn.sc.gov/providers/manualsandguidelines/Documents/HealthCareGuidelines/NursingMgmtSeizures.pdf>

## Appendix C

### Quiz

Ten questions have been prepared to test your knowledge following this section. To demonstrate comprehension of the current section, a score of **80%** is required. A score of **less than 80%** is suggestive of a need to return to the section for further review.

**Instructions: Circle the correct answer**

1. Approximately what percentage of all admissions to a diagnostic epilepsy unit will result in a diagnosis of PNES for patients?

- a) 10%
- b) Less than 5%
- c) 30-50%
- d) The epilepsy unit only admits people with epilepsy

2. Which antiepileptic medication is often prescribed for PNES?

- a) Lamotrigine
- b) Keppra
- c) Diazepam
- d) Antiepileptic medications are not indicated for PNES

3. It is likely that my patient with PNES in the diagnostic epilepsy unit will have been prescribed an antiepileptic medication?

- a) True
- b) False

4. To support an accurate diagnosis, an epileptologist requires:

- a) video capture of a seizure event
- b) Electroencephalograph
- c) blood test
- d) a & b

5. What is seizure semiology?

- a) The study of partial seizures

- b) The study of the physical signs of a seizure
  - c) A pharmacological compound used by epilepsy nurses to prevent seizures in people with PNES
  - d) Rapid eye movement exhibited by a someone mid-phase during a PNES
6. The onset of PNES is often in late adolescence or adulthood but can also occur in children and the elderly:
- a) True
  - b) False
7. Nursing intervention(s) for supporting people with PNES include:
- a) Reminding your patients that PNES is not real
  - b) Medication monitoring
  - c) Encourage your patient to go for a cigarette break
  - d) Maintain the head of the bed at 45 degrees
8. What is an EEG?
- a) A heart test to rule out atrial fibrillation
  - b) A test used to detect abnormal electrical brain activity
  - c) It is a fee which is paid by the patient upon admission to the diagnostic epilepsy unit
  - d) A malformation in the brain responsible for seizure activity
9. PNES are the result of:
- a) Attention seeking
  - b) Epileptic discharge in a patient's brain
  - c) Coping with a stressor such as abuse by a person predisposed to PNES
  - d) A vegetarian diet
10. What is alexithymia?
- a) An enlarged hypothalamus
  - b) A variant of lysergic acid diethylamide
  - c) An inability to identify and describe emotions in one's self
  - d) A diffuse axonal head injury

Answer Key:

1. c 2. d 3. a 4. d 5. c 6. a 7. b 8. b 9. c 10. c



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## **Section 2**

# **Roles of Health Care Providers**

# Roles of Health Care Providers

The interprofessional team members' contributions to the patient's care and how they will complement or synergize your nursing interventions will be a powerful asset. You can help prepare your patient for what they may experience during their admission through understanding all the roles of all the health care providers who may be involved in their care. Furthermore, you may also be able to anticipate the needs of the patient who has PNES and tailor nursing care or unit activities accordingly.

A working understanding in relation to the roles of the health care providers and professionals on your team is central to the patient care in the diagnostic epilepsy unit. In this section, you will learn about the roles of:

- ✓ Patient
- ✓ Psychologist
- ✓ EEG Technician
- ✓ Social Worker
- ✓ Community Support
- ✓ Nursing

Appendix A has a Quiz to challenge your comprehension. A score of less than **80%** is suggestive of a need to revisit the content.

# Roles of Health Care Providers

## Section 2

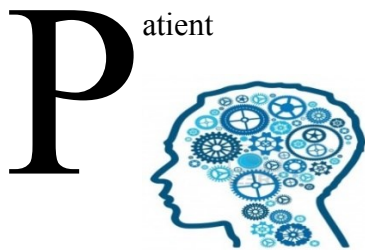
### Learning Objectives

By completion of Section two the learner will be able to:

- List the membership of the interprofessional team working on the diagnostic epilepsy unit team
- Describe how the role of each team member contributes to the care of the patient
- Understand the role of the patient in relation to nursing care and the activities of other professionals on the team.



# Roles of Health Care Providers



The care of the patient is an interest which is shared by all members of the health care team working in the unit. The patient is the focus of the team and its most important member. The patient will inform treatment decisions and the processes which guide the development of the nursing care plan. When patient engagement is high, patients can perceive improvements in their quality of life and can promote early recovery (Sahaya, Dholakia, & Sahota, 2011; Plejert, 2016). The patient will be a great source of information such as, alerting you to a seizure which is about to happen, what helps them recover from an event, the health education needs they may have or ways you may be able to assist them.

**P** **psychologist** Psychologists assess, interpret and treat processes of sense perception, cognition, motivation, emotion, thinking, learning, personality, aberrant behaviours, as well as interactions between individuals and the interactions with the environment. (Lagasse, 2014). Simply put, psychologists are organized by a scientific discipline which examines the mental processes of individuals, interactions with others and the connections between these processes, interactions and the environment. When PNES is suspected, the *Provincial Guidelines for the Management of Epilepsy in Adults and Children* (2015) implore neurologists to refer patients to the psychology service to complete further investigation and treatment (Critical Care Services Ontario, 2015). The psychologist is an integral member of the inpatient team for people with PNES, as the medical condition is

very much related to psychological variables such as, impaired emotional processing, affective dysregulation, characteristic avoidant coping style and exposure to trauma or abuse (Russell et al., 2016). While your patient who has PNES remains an inpatient of the diagnostic epilepsy unit, the Program's psychologist may be consulted to assess the patient, offer a clinical opinion, and complete evaluations or to engage the patient in a brief psychotherapeutic relationship. Psychologists will work with people to help them make desirable changes in their lives. They will also utilize strategies to help individuals manage with stress that they are or are likely to encounter resulting from the interactions between self, others and the environment. At times, a psychology instrument or tool may be used to assess a symptom/cluster of symptoms, trait or ability in your patient. The aim of which is to help to develop a differential diagnosis or a treatment plan which is mindful of the individuals strengths, history, resources and abilities. Psychological tools are protected validated measures which can only be administered by qualified psychologists. For example, the Minnesota Multi-Phasic Personality Inventory (MMPI) is routinely used in the diagnostic epilepsy unit. The MMPI is administered to measure relative indicators of health, personality traits, and psychopathology such as, anxiety, depression, alienation, cynicism, self-esteem, social functioning amongst others (Framingham, 2016). When scored or otherwise completed, the psychologist will use the results from their assessments to identify the ways and means by which the patient might benefit from intervention or treatment. Due to the short length of stay in the diagnostic epilepsy unit, it is understood that the patient diagnosed with PNES will have to engage with an ambulatory or community psychologists following discharge.

## **S**ocial Worker

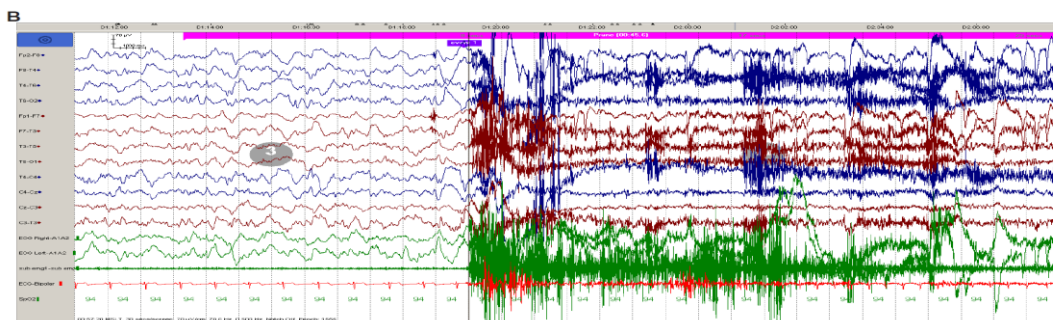


In Ontario, a social worker is a professional who is registered with the Ontario College of Social Workers and Social Service Workers and is permitted to provide health care in a hospital setting for example, a diagnostic epilepsy unit. PNES presents a tremendous social and economic burden on the individual, as well as the deleterious impact on quality of life, these influences can also be significant barriers to health and recovery (Wiseman & Reuber, 2015). A social worker is positioned in a diagnostic epilepsy unit to assist patients to use their own and community resources to manage during and following the inpatient admission. This assistance is particularly helpful in relation to advocacy and



access to patients to connect with public and private agencies or resources. In addition, a social worker may also act as a liaison between the treating team and the patient and family (Canadian Association of Social Workers, 2015). These connections may include working with employers, local or regional social service providers, community agencies or accessing hospital-bound supports such as, transportation assistance. It is important to remember that patients may not know what is available in their community or have the abilities to access service. Part of the role of the social worker is to educate patients about resources and services available to them. In the diagnostic epilepsy unit, a social worker may also assist with the provision of counselling and engage the patient and family in the connection with and navigation of social and community supports (Critical Care Services Ontario, 2015). Given the large geographic area from which your patient may come from, the social worker will also assist with discharge planning and the facilitation of connections in the patient's home-community.

## **E**lectroencephalography Technician



An Electroencephalograph (EEG) is an electroneurodiagnostic test using a machine which can detect abnormal electrical brain activity in a patient. The EEG is completed by an EEG technician and used by the neurologist to diagnose medical problems. The EEG technician is certified by the Canadian Board of Electroencephalograph Technologists to apply or connect to electrodes attached to the brain or scalp of a patient to have a record the electrical activity of the brain. EEGs are of significant diagnostic value when PNES is suspected and when paired with video imaging. Video EEGs have significant diagnostic value and are considered to be the gold standard for diagnostic epilepsy inpatient services as per *Provincial Guidelines for the Management of Epilepsy in Adults and Children* (Mcgonigal, Russell, Mallik, Oto, & Duncan, 2004; Critical Care Services, 2015). EEG technicians will also ensure that the electrodes which are attached to the patient are

recording and will troubleshoot connectivity problems. Given that the video-EEG is completed during their inpatient stay, the EEG recording is considered continuous monitoring which has an aim of capturing all brain activity over a given period of time. EEGs will also be completed for neuropsychological assessments such as, language and memory lateralization (Bogaarts, Gommer, Hilkman, Van Kranen-Mastenbroek, & Reulen, 2016). The EEG may also be used by the neurologist to illustrate the contrast between epilepsy and PNES during the provision of the PNES diagnosis.

## **E**pileptologist



A neurologist is a medical doctor who has specialized in the neurological sciences. An epileptologist is a neurologist with further sub-specialization in epilepsy. The epileptologist will direct the medical care of patients admitted to the diagnostic epilepsy unit. Epileptologist-directed inpatient care following a first seizure is associated with greater diagnostic accuracy, adherence to follow-up and considerably less indirect costs for example, emergency department presentations/hospital admissions or missed work (Fisch et al., 2016). The epileptologist will interpret the results of the diagnostics, consultations and history or other assessments available to formulate and provide the diagnosis of PNES to the patient based on these data. Epileptologists have the training and tests/assessments available to assign an accurate diagnosis of PNES in nearly all cases (Sahaya, Dholakia, & Sahota, 2011; Takasaki, Diaz-Stransky, & Miller, 2016). The epileptologist may involve the nursing staff in family meetings or during inpatient rounding. In addition, the epileptologist will discharge of the patient to the home community or referring hospital with orders and consultations as appropriate to the care plan.

## C community Support



An environmental survey of most communities will identify that there are few formalized community resources especially for PNES. A holistic view of PNES will reveal that there are many community resources from which a person diagnosed with PNES could benefit from such as mental health agencies, housing support, financial assistance, employment support, academic counseling amongst others (Pretorius & Sparrow, 2015). In Ontario, the Epilepsy Support Center (ESC) offers assistance to people with epilepsy and other seizure disorders, including PNES with an aim of helping the individual to self-actualize through life enhancement, education and advocacy (Epilepsy Support Center, 2015). The ESC utilizes a network of like centers in areas outside of London to connect people with supports in their home communities. Just as valuable, the ESC helps people adjust to their diagnosis through peer-peer relationships and reducing marginalization and stigmatization by offering community to those who may not have one. It is community supports such as the ESC which can help a person diagnosed with PNES to impede social isolation, feelings of loneliness and improve depressive mood symptoms (Pretorius & Sparrow, 2015; Spino, Kameg, Cline, Terhorst, & Mitchell, 2016). With the length of an admission of someone with PNES to the diagnostic epilepsy unit being on average three to four days, it is likely engagement in treatment or service for PNES will occur as an outpatient (Moseley, Dewar, Haneef, Eliashiv & Stern, 2016). In London, outpatient mental health support is available and accessed by physician referral to London Health Sciences Centre's Coordinated Access Department (London Health Sciences Centre, 2007). The General Adult Ambulatory Mental Health Service utilizes a multidisciplinary team approach to deliver appropriate individual and group treatment options for individuals with PNES such as emotion regulation groups, cognitive behavioural therapy or day treatment to assist people with the recovery process as examples.

## N nursing



Nurses are the only member of the multidisciplinary team to maintain an around the clock presence with the patients admitted to the diagnostic epilepsy unit. As a result, they have a very important role to play in providing care to patients with PNES. Nurses strive to work together to ensure that the patient care activities are proceeding as scheduled and patient care orders are executed safely and accurately. With the constant presence in the unit, nurses are likely to be the initial responder to a seizure, provide first aid, be engaged with the family, are a very important source of expert health education and interpersonal support (Pfäfflin, Schmitz, & May, 2016). Nurses also act an advocate and as a point of contact between the patient/family and treating epileptologist-sometimes even after discharge from the unit. From the shortest visit to the longest stay, the relationship that is established between the nurse and the patient can have a very positive effect on the outcome of nursing interventions (Sampaio, Sequeira, & Lluch Canut, 2015). Nurses in the diagnostic unit provide high quality holistic care which can help patients/families to adjust to their long standing medical condition or new diagnosis.

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# Roles of Health Care Providers

## Appendix A Quiz

Ten questions have been prepared to test your knowledge of the content. To demonstrate comprehension of the current section, a score of 80% is required. A score of less than 80% is suggestive of a need to return to the section for further review.

**Instructions: Please circle the correct response(s)**

1. What is an EEG?
  - a) A tracing of the patient's cardiac rhythm
  - b) A diagnostic test using a machine which can detect abnormal brain activity
  - c) A surface antigen which is linked to the development of PNES in patients with epilepsy
  - d) The abbreviation denoting an epilepsy epileptologist (general class)
2. Which member of the team is **most** likely to be present with a patient during a seizure?
  - a) Nursing
  - b) Epileptologist
  - c) Pastor
  - d) Social Worker
3. Engaging a patient in their care plan and treatment decisions is likely to promote deterioration in the patient's perceived quality of life?
  - a) True
  - b) False
4. This team member helps to connect patients with resources or assistance in their community:

- a) Social Worker
  - b) Epileptologist
  - c) EEG technician
  - d) Patients do not require assistance connecting with community resources
5. Which member of the team would facilitate the administration of an MMPI?
- a) Nursing
  - b) Psychologist
  - c) EEG technician
  - d) Hospital Pastor
6. The EEG technician will use the results of the EEG test to diagnose patients with epilepsy or PNES:
- a) True
  - b) False
7. Which organization in London offers peer-peer relationships to help people adjust to having seizures?
- a) London Walk-in Clinics
  - b) Epilepsy Support Center
  - c) London Homeless Coalition
  - d) Salvation Army
8. What is the title of the professional who has trained as a neurologist but has specialization in epilepsy care?
- a) Chief Neurologist
  - b) Epilepsy Fellow
  - c) Epileptologist
  - d) Psychologist
9. Which diagnostic test results may be used by the epileptologist to contrast an epileptogenic from a psychogenic seizure when providing a diagnosis to the patient?
- a) Blood Pressure
  - b) Blood test
  - c) EEG
  - d) EMG



10. When PNES is suspected, which team member does the *Provincial Guidelines for the Management of Epilepsy in Adults and Children* suggests becomes involved in patient care?

- a) Occupational Therapist
- b) Psychologist
- c) Clinical Pharmacist
- d) Pathologist

Answer Key:

1. b 2. a 3. b 4. a 5. b 6. b 7. b 8. c 9. c 10. b

# Section 3: ‘Here for Classification’

Section 3  
**'Here for classification'**

**Learning objectives**

Upon completion of section three, the nurse will be able to:

- Define stigma and advocacy
- Describe how stigma can influence quality of life in people with PNES
- Articulate the nurses responsibility to advocate for PNES patients
- Identify aspects of the inpatient admission which can be detrimental to your patient's ability to cope
- Communicate the influence of derogatory nursing language as it relates to describing patient experiences with PNES

### **Introduction to Section Three**

Patients who are suspected of having PNES or have been diagnosed with PNES while admitted to the epilepsy diagnostic unit can face many challenges. Some of these challenges may include medical problems, interpersonal difficulties or financial questions. However, there is another challenge which is more insidious but no less damaging. Section 3 introduces the learner to *stigma* and the closely related need for nurses to be vocal advocates for their patients with PNES. The admission to the diagnostic epilepsy unit places significant demands on the patients. Nursing care that is responsive to the needs of the individual with PNES will assist them to adjust to what will be very substantial and meaningful changes in personal context and identity for some individuals. Nurses can work with patients prior to their discharge to prepare for the next step in their healthcare journey. Section 3 will consolidate information from the prior two sections drawing upon your acquired knowledge of PNES and exposing the experience of your patient.

## Introduction to Stigma and Advocacy



# Stigma

People with PNES can face challenges which make managing their medical condition or engaging in treatment very difficult. Stigma is one of these challenges. Stigma is the 'lived experience' of a person where discrimination and the anticipation of discrimination influences cognitive and emotional processes overwhelming the individual's ability to disregard these messages further exacerbating discrimination (Rüsch, Brohan, Gabbidon, Thornicroft, & Clement, 2014). The Canadian Mental Health Association (2016) describes stigma as a stereotype in which it is a reality of life for people with PNES. It is stigma which acts as one of the greatest barriers to people with mental illnesses living a complete and satisfying life. Self-stigma then describes the internalization of the discrimination and stereotypes which impacts self-esteem and ultimately, self-efficacy and quality of life (Corrigan et al., 2010). For people with PNES, stigma may exist in their interactions with their environment, as well as their interactions with the medical and social systems. As a non-epileptiform seizure disorder, PNES is out of the individual's control and can happen at distressing times or events. Stigma may be present in relationships and social interactions in the form of both perceived and self-stigma as the individual considers admission to the diagnostic epilepsy unit for classification of what will end as a diagnosis of PNES. Receiving a mental health diagnosis such as PNES, accepting and disclosing the medical condition as something other than epilepsy can be frightening to the person. It can also have a considerable impact on adjustment which may influence subsequent quality of life (Rüsch et al.). Factors such as co-morbid medical conditions, impaired emotional processing, exposure to medications, seizure worry or ineffective coping responses can further influence quality of life for people with PNES and be a source of stigma for the individual (Myers, Lancman, Laban-Grant, Matzner, & Lancman, 2012). The detrimental effects of stigma can undermine an individual's ability to manage or recover from PNES. It can also influence interactions of the patient during the admission to a diagnostic epilepsy unit.



# ADVOCACY

Unfortunately, the stigmatization of people with PNES can exist in the medical system which includes nurses working in diagnostic epilepsy units.

Negative attribution to PNES, such as ‘fake’, attention seeking or a perception that the seizures are under the patient’s control, is common amongst nurses and may influence interpersonal nursing dynamics and quality of nursing care (Worsley, Worsely, Whitehead, Kandler, & Reuber, 2011; Sahaya, Dholakia, Lardizabal, & Sahota, 2012). The attitudes of health care providers can not only act as a barrier to accessing healthcare, but can also influence the quality of care a patient with PNES may receive when stigma is felt by the patient. Advocacy involves engaging others in evidence driven change and to speak out against inequities or discrimination to influence nursing practice (Canadian Nurses Association, 2016). In practice, nurses need to advocate for the populations that they work with, in particular, the vulnerable and those at risk (Water, Ford, Spence, & Rasmussen, 2016). It is then essential that when you hear others referring to PNES as ‘fake’ or ‘attention seeking’ behaviours or ‘not real’ that you correctly identify this as an opportunity to clarify PNES is a serious and legitimate medical condition



## **C**oming into the Unit

An admission to a diagnostic epilepsy unit can be a very stressful time for families and the patients admitted for classification and diagnosis. Admission to the unit may remove coping strategies, relationships or routines which have aided the person to manage the seizures. Without these supports, the individual may decompensate and regression may be seen. As a result of geography, finances, organizational policies (no smoking on

hospital grounds), unit expectations amongst other causes may act as factors which limit or collectively act as barriers to coping and adjustment. Nurses may identify the decompensating as impaired emotional processing, conflict, more somatic complaints, psychological distress and ineffective coping responses such as avoidance or verbal outbursts (Novakova, Howlett, Baker, & Reuber, 2015). It is important that the interactions with a patient who is unsettled are not interpreted as ‘attention seeking’ or exhibiting bothersome behaviours. Instead, recognition of the challenges experienced by your patient can be used to tailor your nursing care plan and discussions with the medical team. From unit one, you know PNES is often misdiagnosed as epilepsy and receiving this diagnosis can be upsetting, incongruent with identity and broaden the feeling of angst that the patient may feel inside (Rawlings & Reuber, 2016). A holistic assessment of your patient’s needs will guide your nursing care plan and support your purposeful interactions in the unit. The period of time surrounding diagnosis of PNES and the time which follows should be anticipated by nurses to be a moment in your patients’ journey when they may require additional support to promote adjustment and preparation for the next steps in their healthcare journey (Pretorius, 2016; Salinsky, Storzbach, Goy, Kellogg, & Boudreau, 2016; Takasaki, Diaz Stransky, & Miller, 2016). A holistic assessment of your patient’s needs will guide the development of your nursing care plan and will support your purposeful interactions in the unit.

**we can  
help**

## **P**reparing for Discharge

A diagnosis of PNES will often signal a discharge order from the diagnostic unit and the Epilepsy Program. A diagnosis of PNES is not however an indication that care for the patient should be pared back or stopped. Once the epileptologist makes the diagnosis, nursing care should be responsive and begin to prepare the patient for the next step in their health care journey. Prior to discharge, it is likely that your patient diagnosed with PNES will be seen by the program



psychologist and an inpatient psychiatric consultation may be completed in some cases (Acton & Tate, 2013). Nursing staff can prepare their patients for these contacts by providing health teaching about the role of mental health professionals and how they may be of assistance. Helping to prepare your patient for a consultation prior to discharge will be beneficial in the short term. It is purposeful engagement and health teaching about ambulatory services and community supports which will declare what will happen once they leave the unit. Nurses can support the patient to engage in treatment following discharge by promoting a relationship with community support services or the ambulatory mental healthcare program. When diagnosis is provided during the admission to the diagnostic epilepsy unit and treatment for PNES is accessed, a significant and sustained reduction in health care utilization is probable (Anderson et al., 2016; Duncan, Anderson, Cullen, & Meldrum, 2016). Health education provided by nurses has been demonstrated to be an effective means to increase knowledge and familiarity with treatment, as well as promoting a better experience in tertiary patients preparing for discharge (Gilliam, 2016). Our nurses are integral to providing an excellent patient experience in the unit and need to help to encourage the relationship with the next healthcare provider, in order for the work started in the epilepsy unit to continue. Nurses can advocate for referrals to be made to professionals in the ambulatory mental health service of the hospital, engagement with community and social supports, as well as to provide patients with information that they can refer to when they are ready. When nurses are **responsive** to the evolving needs of their **patient** diagnosed with **PNES**, the results associated with **advocacy** and **promotion** of **engagement** with **supports** and **treatment**, **your effort will make a difference.**

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### **Case study**

Consider the following situation: A 56 year old recently divorced female presents to her family physician in her small town reporting that she had two “seizures” this past Sunday morning. Suspecting epilepsy, the physician orders a titrating dose of an antiepileptic medication, advises her that her license is suspended, but does not discuss a referral to a diagnostic epilepsy unit for classification. Three days after having met with her physician, she is found seizing by a neighbour and rushed to emergency care via ambulance in apparent status epilepticus. Medical management suggests emergent intervention with benzodiazepines which was initiated by the emergency department physician. The seizures did not respond to repeated benzodiazepine administration. The patient required intubation due to anesthetic-induced respiratory insufficiency. Intubation damaged lung tissue and patient was admitted to ICU. A stat EEG revealed patient was not in status epilepticus. Once recovered, admission to diagnostic epilepsy unit confirmed diagnosis of PNES. Patient was discharged to the care of her family physician.

### **Questions for Reflection**

What limits the certainty of a diagnosis of epilepsy made in the above primary care setting?

Did the emergency physician respond appropriately considering what information was known to him/her at the time of the patient’s arrival to the hospital by ambulance?

How effective would epilepsy rescue medications such as, benzodiazepines be for the woman in this situation?

In which ways could have the nurses of the diagnostic epilepsy unit encouraged the care episode to continue after discharge from the unit?

Is it possible that this sequence of events could reoccur for someone diagnosed with PNES?

What are the implications for suspending this person’s driver license?

## Conclusion



Congratulations! You have completed the Self-Directed Psychogenic Non-Epileptic Seizure Learning Module for Nurses. This resource was created to address a need for nurses to have access to PNES for example, specific information prior to starting in the epilepsy unit. The PNES population which composes a significant portion of the admissions to the diagnostic epilepsy unit often are underserved as a result of healthcare providers who are inexperienced with or unaware of the needs of this patient group. At LHSC, these providers have been historically been nurses who have transferred into the unit from another area as well or students and newly graduated nurses. Experience working with patients who have PNES will allow for you to begin anticipating the needs of your patients prior to confirming signs or events. From completion of this module, it is hoped that you will take with you an understanding that your patient with PNES requires validation of their experience. Beyond validation, your patient deserves supportive nursing care which is sensitive to their individual needs and education to promote a successful transition to treatment following diagnosis. Please be an advocate and correct misunderstandings about PNES by challenging stigmatizing comments or attitudes- *it starts with you.*



Please also refer to this resource for a review or to structure your teaching when you have a nursing student on the unit.



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